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# **An occupational therapy perspective on diabetes**

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BSc

Thesis submitted in partial fulfilment of the  
requirements for the degree of  
Doctor of Philosophy

Lancaster University (University of Cumbria)

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## **Declaration**

This thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Annabel Youngson

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# **Abstract**

The incidence of diabetes in the United Kingdom is increasing and its impact on health and social care costs is significant, with considerable personal consequence for the individual with diabetes. Current approaches to managing or preventing diabetes include education, self management and lifestyle change but the evidence suggests that some people are unwilling or unable to make lifestyle changes recommended for better health and wellbeing.

This qualitative study examined the potential role of occupational therapy, with its focus on individual and daily occupations, to enable people with diabetes to manage this condition in the context of their own lives. Using a process of intuitive inquiry, it comprised three separate studies all using semi-structured interviews. The first, designed to explore the lived experience of diabetes, involved seven people with a diagnosis of type 1, type 2 or pre-diabetes. Findings were shared with participants using a felt metaphor of charting a course of health and well-being through a choppy sea. The second study involved ten occupational therapists with type 1, type 2, gestational or pre-diabetes and examined the use of metaphor as a means of understanding the lived experience. In addition the potential role of occupational therapy was explored with participants. Using knowledge gained from studies 1 and 2, the third study involved five people with type 2 diabetes and used metaphor as a means of exploring difficulties and successes in diabetes self management. All three

studies were then drawn together to consider the use of metaphor and the potential role of occupational therapy in diabetes self management.

From the findings a model of the occupation of diabetes self-management is proposed along with a framework for occupational therapy intervention in diabetes self-management that focuses on the professional belief of the impact of occupation on health and wellbeing and considers the individual in their particular life context.

# Public Output

The following publication, papers and exhibitions have resulted from this research.

## Publications

Youngson, A., Cole, F., Wilby, H. and Cox, D. (2015) The lived experience of diabetes: Conceptualisation using a metaphor. *British Journal of Occupational Therapy* 78 (1) 24-32.

## Peer reviewed conference papers and posters

Occupational Science Europe Conference, Cork, S Ireland, Sept 2013

- *Stitching up the thesis: an exploration of the occupation of research.*  
Paper

16<sup>th</sup> International Congress of the World Federation of Occupational Therapists, Yokohama, June 2014

- *Towards an occupational therapy solution for the prevention and/or self management of diabetes.* Poster.
- *The occupation of research and the occupation of art: using occupation to describe occupation.* Paper.

College of Occupational Therapists 38<sup>th</sup> Annual Conference, Brighton, June 2014

- *Diabetes: charting a course of health and wellbeing in the sea of life.*  
Paper.

College of Occupational Therapists 39<sup>th</sup> Annual Conference, Brighton, July 2015

- *What is the unique role of occupational therapy in diabetes care?*  
Paper.
- *Battle and Control. Conceptualising diabetes through metaphor.*  
Poster.

## **University of Cumbria conference papers**

University of Cumbria Doctoral Colloquium, Lancaster, July 2013

- *Living with Diabetes how does it feel?* Paper.

University of Cumbria Doctoral Colloquium, Lancaster, July 2014

- *Battle and Control: Conceptualising diabetes through metaphor.*  
Paper.

Cumbria Research and Enterprise, University of Cumbria, Lancaster, July 2014

- *Picture that! Using creativity to broaden your impact.* Paper.

## **Other presentations:**

OT4OT 24 hour virtual exchange, October 2013

- *From practitioner to researcher – transitions explored through mixed media artwork.* Invited speaker.

## **Exhibitions:**

Occupational Science Europe Conference, Cork, S Ireland, Sept 2013

- Exhibition of mixed media art work related to study.

Northumberland, Tyne and Wear NHS Trust Allied Health Professions Conference,  
Durham, October 2013

- Invited to exhibit art work related to study

University of Cumbria Doctoral Colloquium, Lancaster, July 2014

- *Stitching up the Thesis: an exhibition of mixed media research art work*

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**Figure 1 Green shoots**

*Created at the start of the research, this piece represents my initial ideas. The following is my reflection at the time. "This 'green shoots' work is created by using a needle felting tool and lightly punching the yarns into the felt. The green shoots are all the ideas that I have around the research. Some are small and in their infancy, some have travelled a distance but are not yet fully formed, some have gone further but are tightly bound up still, although starting to unravel. Some have been discarded; others have changed direction from time to time but are still strong. The beads are the gems of ideas that are yet to find fruition. Clearly there are lots of themes around growth, my own and the research, although I think it would be difficult to separate those at the moment."*



# **1.0 Introduction**

## **1.1 Chapter Outline**

This introduction will set the scene of the study, which took place between 2012 and 2015. It will begin with the personal context and a rationale for the study. An overview of the decisions made while developing the study follows. The next section introduces the artworks and reflexive additions to each chapter. Finally the construction of the thesis will be explained with a description of the chapters which follow.

## **1.2 Personal Context**

This study is concerned with the role of occupational therapy in the possible prevention and self management of diabetes. This is an area of occupational therapy that is not commonly practised (Pyatak, 2011a) but which may lend itself to an approach that is based in the life context, and not just on the medical aspects, of people with this long term condition.

Initial ideas began when I was working as an occupational therapist on an acute stroke ward. Stroke can often have very devastating consequences and, after three years on the ward, I began to consider how it might be possible to use my occupational therapy skills to prevent people having a stroke in the first place. I became aware that a large proportion of the people on the stroke ward had diabetes and many were struggling to manage their condition. Diabetes is a significant risk factor for stroke (Woodward, 2015) and the incidence of diabetes

worldwide is increasing. Diabetes UK, using feedback from the International Diabetes Federation, the Office for National Statistics population data and the Quality and Outcomes Framework 2012/13, estimate that in the UK there are currently 3.8 million people diagnosed with diabetes, over 1 in 20 of the UK population, and a further 633,000 with undiagnosed type 2 diabetes (Diabetes UK, 2014a). They estimate that up to 80% of cases of type 2 diabetes could be delayed or prevented (Diabetes UK, 2014b). Apart from stroke, the long term complications of diabetes can include heart attacks, renal failure, blindness, and amputations (Health and Social Care Information Centre, 2013).

The current thinking is that people with diabetes should be able to manage their condition – and in particular to ensure that metabolic control - blood glucose levels, blood pressure and cholesterol are at normalised levels to prevent further complications (National Collaborating Centre for Chronic Conditions (NCCC), 2008). The National Institute for Clinical Excellence (NICE) guidelines (2003) and the Diabetes National Service Framework (Department of Health (DOH), 2002) are concerned with supporting people to self manage through lifestyle change and education in these areas (DOH, 2002; NICE, 2003). Prediabetes, also known as borderline diabetes, is a condition in which blood sugar levels are elevated but lower than the threshold for diagnosis (Mainous III et al, 2014). The NICE (2012) guidance recommends prevention of progression into diabetes through lifestyle change programmes (NICE, 2012).

Occupational therapy (OT) is an allied health profession based on the belief that engagement in and balance of occupations leads to better health and wellbeing (Wilcock, 2006). It is concerned with the meaning and purpose that people place on occupations or daily activities of life (Christiansen and Townsend, 2011). A core belief of the profession is that being able to live congruent with one's personal meanings and values – occupational integrity – is essential for wellbeing (Pentland and McColl, 2008). Occupational therapists use core skills to empower people to make choices, to achieve a personally acceptable lifestyle and maximise health (College of Occupational Therapists (COT), 2013). This led me to consider how the profession of occupational therapy might contribute to enabling people with diabetes to manage their condition to prevent these complications (such as stroke) or indeed to help prevent people developing diabetes in the first place.

### **1.3 Rationale**

From a review of the literature, it became apparent that while the long term treatment of diabetes is currently primarily a medical approach based on education, lifestyle change and self management, the evidence suggests that there are many barriers to successfully incorporating medical advice into individual lifestyles (Mulvaney, 2009; Nagelkerk et al, 2006).

The occupational therapy profession has recognised the potential for developing its presence in the field of public health and health promotion due to its belief in the relationship between occupation and health and well-being (COT, 2008;

Scriven and Atwal, 2004). However there is little evidence of this happening in practice (Molineux and Baptiste 2011; Moll et al, 2013; Wood et al, 2013).

The rationale for this study was thus to consider how occupational therapy, with its focus on individual and daily occupations, might support a person with diabetes to improve self management for health and wellbeing. The fact that this was not already an area of occupational therapy practice suggested that an exploration of this potential was an important development for the profession. In addition an exploration of occupational therapy beliefs, values and scope of practice to see how intervention might fit with existing healthcare practices and policy was also indicated as a requirement to understanding why this was not an area of practice. The rationale was thus to contribute to the knowledge base of the profession and to consider how occupational therapy practice might complement existing services in diabetes self management.

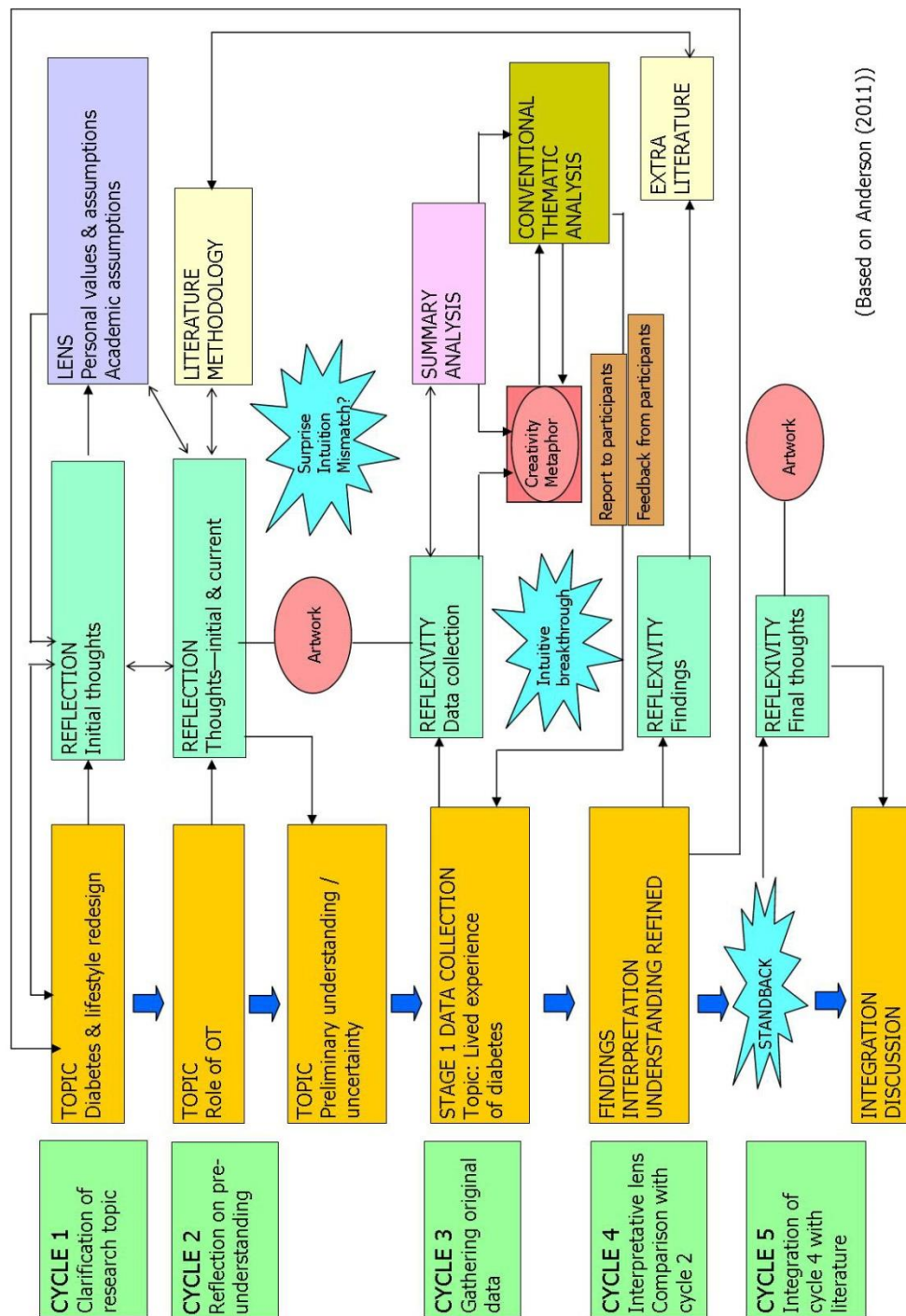
#### **1.4 Decisions Made in the Development of the Study**

My initial ideas were based on devising an occupational therapy programme, using the core principles of the profession, to enable people to make lifestyle changes, to attain the desired metabolic outcomes. This was an example of my thinking being influenced unwittingly by my eleven years of working in hospital environments where I would use my skills around occupation to 'do' to others, through a prescribed intervention, with the outcomes expected of the hospital culture (Leape et al, 2012).

However, my ideas were challenged by reading *Needles* (Dominick, 1999). Charmaz (2006) recommends using autobiographies of people with chronic or long term illness as a source of insight for sparking ideas. *Needles*, about one woman's journey with type 1 diabetes, had a profound effect on my thinking and changed the way I looked at my approach which, on reflection, was too simplistic and influenced by the bio-medical viewpoint with its focus on metabolic control as an outcome. In this memoir Andie Dominick rebels against the whole experience of having diabetes and having to 'conform' to what was expected by the medical profession. It became apparent that there would be potential difficulties in devising and delivering a prescribed occupational therapy intervention and the book made clear that there were any number of approaches that would need to be taken, depending on the needs of the person concerned.

The memoir raised profound questions for me about how occupational therapy might contribute to the current self management approach and led me to question the time-bounded interventions (in the sense of a 'one size fits all' approach) that are devised to meet the needs of people with a particular condition. In addition I realised that I did not have a secure grounding in what it was like for someone to lead a daily life with diabetes. This led me to consider starting the study from the perspective of the individual with diabetes, rather than from a medical/occupational therapy viewpoint.

These initial ideas are represented in Cycles 1 and 2 of the intuitive inquiry process (Anderson, 2011) which is outlined in Figure 2. This diagram represents



(Based on Anderson (2011))

Figure 2 Intuitive Inquiry Process for Study 1

KEY TO FIGURE 2			
	Cycle		Colour represents study 1
	Stages through cycle		Intuitive breakthrough moment
	Reflexivity		Artwork describing process
	Forward / back movement		Cross-over between artwork and metaphor

my interpretation of the process and shows the cyclical nature and relationship between the various steps that were taken at this stage of the study. The process of intuitive inquiry, which is used in each of the stages, will be discussed more fully in Chapter 8 Methodology and Chapter 9 Study Design.

Cycle 3, in Figure 2, is where I began to discard some of my original ideas and to start to research people's lived experience of type 1, type 2 and pre-diabetes. A qualitative approach using semi-structured interviews to explore this lived experience would, I felt, enable a deeper understanding of the personal and occupational (rather than medical) nature of living with diabetes.

As the study progressed I began to challenge my assumptions, both about occupational therapy and the medical approach to long term conditions. I became aware of the language being used to describe people with long term conditions and the language that people used to describe their own experiences which appeared to sometimes contradict each other. In addition the professional language of occupational therapy, and lack of a clear definition, appeared to create boundaries to practice (Creek, 2010; Rebeiro Gruhl, 2009) and I questioned my own professional terminology.

As part of the process of Cycle 3 of intuitive inquiry (Anderson, 2011) I conceptualised the experiences of the study 1 participants in a felt metaphor (see Figure 22 in Chapter 10 Study 1 Findings and Discussion, page 186) to convey

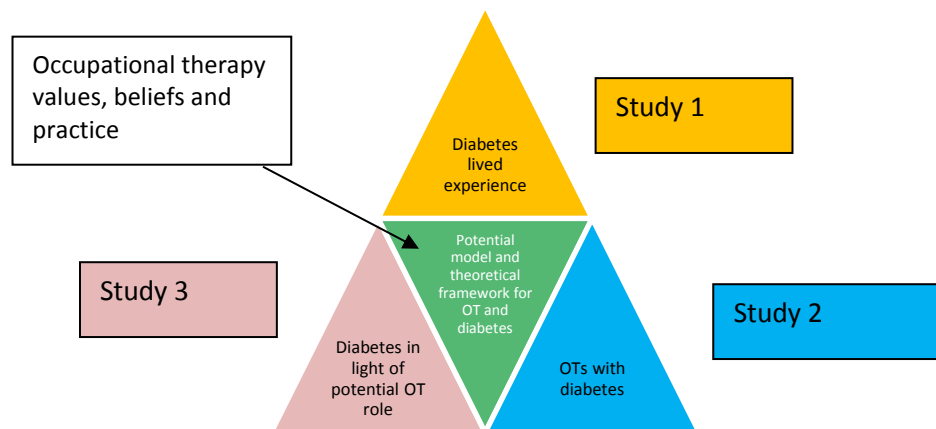
both the impact of people's lives on their ability to self manage, and the corresponding impact of diabetes on lifestyles (Cycles 4 and 5).

The second part of the intuitive inquiry process started with a consideration of the role of occupational therapy in the context of these lifestyles, which was then explored with occupational therapists with diabetes, thus starting a new cycle of inquiry. I also introduced the concept of metaphor as a therapeutic tool for understanding diabetes by asking the occupational therapists to conceptualise their own experiences using metaphor. This gave an opportunity to further understand the realities of living with diabetes and explore the use of metaphor. Study 2 allowed for a discussion with those participants as to how they might have used occupational therapy concepts in their own self-management and how it might be applied to others with diabetes. This enabled an exploration of occupational therapy's perspective and the ways in which it might be integrated into a healthcare team.

The third part of the study was originally intended to compare the potential occupational therapy approach from study 2 with existing occupational therapy practice in this field. However as Pyatak (2011a) suggested this was not an area of healthcare practice that occupational therapists were involved in, except as an underlying condition to another illness (as in my experience on the stroke ward) and, despite several attempts to find participants that met the criteria, I was unable to recruit to this stage. Instead, using knowledge gained from studies 1 and 2, I interviewed people with diabetes in the light of the potential



occupational therapy role and used metaphor as a means of exploring difficulties and successes in self management.



**Figure 3 Overview of the research study**

Figure 3 summarises these three studies. To aid differentiation between the three studies in the following chapters, the findings from Study 1 are highlighted in yellow, the findings from Study 2 in blue and the findings from Study 3 in pink, as per this diagram. Throughout the stages of the study the aim was to consider a potential model of the occupational nature of diabetes and a theoretical framework for occupational therapy in diabetes that was based on the findings and the needs of the participants. This is reflected in the middle section of Figure 3.

## **1.5 Artworks and Reflexivity**

My own research journey became an integral part of the methodology, as will be explained in the following chapters. My thinking about myself as an occupational therapist, moving from practitioner to researcher, was explored through the use of mixed media artwork and these artworks became a metaphorical representation of my thinking at the time. Early artworks were published on the

Everyday Occupation Blog (Hasselkus, 2013). As mentioned in the previous section, the development of these artworks led to conceptualising the experiences of the Study 1 participants in a felt metaphor.

Each chapter of the thesis is preceded by an example of a piece of art work with an explanation (written at the time of its creation) as to its contribution to, or comment on, the study. These are considered important as part of my own development and to show evidence of reflexivity. Reflexivity has been defined as a means by which the researcher analyses their own role within the study (Finlay, 2002a). This can be demonstrated through introspection and reflection (Finlay, 2002b); examining where personal and professional assumptions, values and beliefs might affect interpretation (Cutcliffe, 2003; Mauthner and Doucet, 2003; Nunkoosing, 2005) or by attempting to put these to one side by means of bracketing (Caellie et al, 2003; Tufford and Newman, 2010). The complexity of reflexivity is discussed further in the Study Design chapter. In addition to the art works I kept a research study diary consisting of a daily schedule, a methods log/decision trail plus reflections on progress, literature, interviews, and findings (Krefting, 1991) and excerpts from this diary, printed in *Lucida Handwriting font*, are included at the end of every chapter to show further evidence of reflexivity. Although these are necessarily out of context of the whole diary, they are intended to demonstrate my questioning of the literature, a reflexive awareness of where I am in the research process, openness to intuition (Anderson, 2011) and to consider the interactions between myself as researcher and the participants (Green and Thorogood, 2009).

## **1.6 Structure of the Thesis**

Each of the chapters is now introduced to help situate the study into other work in this area. The thesis is structured to show the development of the study, to ground it in the existing research literature and to show my own progress throughout this process.

### **1.6.1 Literature Review**

Chapter 2 introduces the Literature Review and sets the context. As there are four distinct parts to the Literature Review these are divided into separate chapters.

Chapter 3, Diabetes, discusses the nature of diabetes, the prevalence and costs to the health service in the United Kingdom (UK). It examines current research on approaches to diabetes self management through education and care planning, debating non compliance, barriers, outcomes and sustainability.

Chapter 4, Occupational Therapy, analyses the definitions, theories and philosophy of occupational therapy; its role in medicine; and its perspective on health. Occupational science, the study of occupation, is introduced. In addition the chapter explores the research evidence on occupational therapy's role in health promotion and its possible place in the current prevention and management of diabetes.

Chapter 5, Health Policy and Self Care, critically examines the policy, procedures and models of public health and examines the need for health promotion in relation to the growing costs of the National Health Service (NHS). It analyses the current models for long term conditions and chronic illness and how these relate to approaches to self management.

The metaphors and language of ill health abound in practice and in the research literature. Metaphors of battle and paternalism within the 'medical model' are common place (Childress, 1997; Hamilton, 2012; Radley, 1995). Chapter 6, Metaphor and the Language of Ill Health, explores the impact of this language on both the professionals and on the people who have long term conditions, and the potential of metaphors to create or maintain stigma and stereotypes (Penson et al, 2004; Petersen et al, 2001; Sontag, 1978).

The Literature Review concludes in Chapter 7 with a summary and addresses the aims of the study and the research question.

### **1.6.2 Methodology**

This study explores the experiences of people with diabetes and explores possible occupational therapy interventions that are in keeping with and honour both the needs of the participants and the core values of occupational therapy. To ensure that the methodology reflects these principles, the overall framework for this qualitative study is that of intuitive inquiry (Anderson, 2004; Anderson, 2011). Intuitive inquiry has been described as *"a search for new understandings through the focused attention of one researcher's passion and compassion for*

*oneself, others, and the world*” (Anderson, 2006, p.2). Chapter 8 defends the use of this methodology informed by creativity, reflection, phenomenology (Finlay, 2011; Smith et al, 2009), metaphor-led discourse analysis (Cameron, 2003; Cameron and Maslen, 2010; Fairclough, 2001) and heuristic research (Moustakas, 1990). This combination of different perspectives and methods is described by Denzin and Lincoln (2005) as a ‘bricolage’ and allows a deeper exploration of the complexities of human experience (Nolas, 2011). However the need for cohesion using these different interpretations (Frost, 2011) is also debated. Chapter 8 also includes my ontological and epistemological stance and a discussion of how the methodology reflects the values and philosophy of occupational therapy.

### **1.6.3 Study Design**

The Study Design (Chapter 9) addresses the procedure, ethics, sampling and recruitment, data collection and analysis. As stated previously, the research study is divided into three stages:

- Study 1:       The lived experience of diabetes
- Study 2:       The experiences of occupational therapists with diabetes – use of metaphor and views on the potential of occupational therapy in the self management of diabetes
- Study 3:       The lived experience of diabetes in the light of the potential occupational therapy role

The development of these stages is described in the chapter along with a consideration of the credibility and trustworthiness of the research study.

### **1.6.4 Findings**

The findings and initial discussion are described in Chapters 10, 11 and 12 in terms of these three study design stages. The lived experience, the use of metaphor and the potential role of occupational therapy are revealed and discussed.

### **1.6.5 Theoretical Discussion and Conclusion**

The theoretical discussion in Chapter 13 brings all the threads of the study together. The limitations of the study are examined and the findings are considered as a whole in relation to the research question. An occupational therapy model, The Model of Human Occupation (MOHO) (Kielhofner, 2008) is used to conceptualise diabetes self management as a distinct occupation and a framework for occupational therapy in relation to diabetes is proposed. The thesis concludes in Chapter 14 with a consideration of new knowledge, the importance of the study and recommendations for future research in this area.

## **1.7 Summary**

This project began as a somewhat naive understanding of a possible lifestyle change occupational therapy intervention to enable people to manage their diabetes. It developed into an exploration of the lived experience of diabetes; an analysis of the use of metaphor as a tool for understanding those experiences; and an examination of the core values, philosophy, language and practice of occupational therapy in relation to diabetes. What emerges is a proposed model of the occupation of diabetes self-management and a framework for the positioning of occupational therapy as an integrated approach, within a diabetes

healthcare team, to enable the health and wellbeing of people living with diabetes. The following chapters detail the development of this study. Before that I include the first of each chapter's excerpts from my reflective diary. This one considers orthodoxy and my assumptions about the study.

*A reflection on orthodoxy and a questioning of my own stance as researcher:*

*I have been reading a book by Silverman (2007) about the orthodoxies which guide the commissioning of social research. In the 'explanatory' orthodoxy he suggests that everything people do is defined by society and certain variables like social class, gender or ethnicity - and that this then gives rise to certain types of social research based on these variables. Silverman went on to argue that this results in coming up with all sorts of explanations for the phenomena rather than really taking the time to understand how the phenomenon works. It brought me to a bit of a halt - this seemed to completely mirror the initial ideas I had about the study and my assumptions that by offering a programme based on some sort of lifestyle change I could 'help' people to manage their diabetes, without first understanding what all the issues are. Did this mean I had just bought into this orthodoxy, without being aware of it at the time? How had I been so blind about my assumptions? What had led to this blinkered view and how might the study have been different if I hadn't read Needles and taken the research a different way? I thought back over the initial reading I had done around diabetes and wondered whether, in my naivety I had just accepted that it was all about the numbers. I even prided myself on being a client-centred therapist. Was this blinkered too? Exploring the phenomenological lived experience showed me that those assumptions weren't right - and by choosing a phenomenological approach I recognised that I needed to get this perspective to understand the issues. What I didn't realise before I started was what it would reveal for me and to me (July 2014).*



**Figure 4 Scratching the Surface**

*I covered a piece of paper with gesso and started making marks and shapes on it. I then started painting and it became a picture of trees with light fields in the background. The trees symbolise knowledge but also that at the moment it feels like I am just scratching the surface. Under the bark are all the patterns and colours and richness that the gesso techniques have created. I later showed it to Mum and she observed that the trees seem to be a barrier beyond which is the lightness of the background - these seem to symbolise the obstacles that are in front of me at the moment which I will have to work around or through to get to the answers of the study.*



## 2.0 Introduction to Literature Review

Initial searches of the literature were carried out using the University of Cumbria Quest system which searches over 40 databases, the university's journal collections and library catalogue. See Appendix 1 Search Strategy for further details of the Quest system. In addition manual searches of editions of the *British Journal of Occupational Therapy* since 1997 plus an electronic search of all occupational therapy journals on line available via the College of Occupational Therapists (COT) website were completed. Text books and Ebooks from the University of Cumbria library and COT library were sourced along with public health documents from the Kings Fund, The Health Foundation and the Department of Health websites. Key areas included occupational therapy, diabetes, public health, metaphor, research. Within each area key words and combination of key words were searched (eg in occupational therapy these included professional behaviour, competence, language, values, practice). Appendix 1 Search Strategy lists all key words. In line with intuitive inquiry (Anderson, 2011) initial literature searches in cycles 1 and 2 were supplemented with further searches in cycle 4 of each study (see Figure 2, p.6). Journal articles were appraised using tools and checklists from the Critical Appraisal Skills Programme (CASP, 2014a and 2014b).

The Literature Review which follows is divided into separate chapters for ease of reading. As this study is focussed on the potential role of occupational therapy in enabling people to manage their diabetes, the literature review starts with

examining diabetes and then occupational therapy. Chapter 3, Diabetes, discusses the nature of diabetes and the current impact on the UK Health Service. The chapter examines the literature on approaches to diabetes self management, and the debate around non-compliance and sustainability, with a view to exploring where occupational therapy's occupational perspective on health might offer alternative approaches.

Chapter 4, Occupational Therapy, explores definitions of occupational therapy, occupation and wellbeing. It examines the core theories and philosophy of the profession, occupational therapy's role in medicine and occupational perspective on health. It also examines occupational therapy's role in health promotion and its place in the current prevention and management of diabetes.

Chapter 5, Health Policy and Self Care, reviews the literature on public health and health promotion in the UK to set the context for current policy on self management in long term conditions. It examines the current models of care on which health policy is based. It addresses the role of Allied Health Professionals in public health and makes links to the previous chapter on occupational therapy's specific role in this area.

As indicated in the Introduction, the use of metaphor in the language of medicine and ill health became a significant extra layer of interest as the study progressed. The literature was explored for definitions of metaphor, examples of its use in healthcare, the potential of metaphors to create or maintain stigma or

stereotypes, and the value of metaphor in understanding individual illness perspectives. These are discussed in Chapter 6, Metaphor and the Language of Ill Health.

There are many overlaps between these Literature Review chapters and these are summarised in Chapter 7. This chapter also returns to the focus and aims of the study and proposes the research question. The following reflection was written after reading the literature on diabetes and considers the impact on the progress of the study.

*A reflection on reading the literature:*

*I've been reading and reading the literature. From the articles lots of themes are starting to emerge which may need to be probed in the interviews: journey, gender, changing roles, sense of normal, balance, disbelief, loss, devastation, fear, depression, conflict, quality of life, medical condition, skills for self management, attitudes of healthcare professionals, self testing, active involvement in decisions, living with chronic condition, shock of diagnosis, knowledge of diabetes, locus of control, choices, looking for knowledge, support networks, changes to activities of daily living, age differences, resistance to change, impact of habit, patterns and behaviour on self management, social circumstances, environment context. Some themes are around the fact that management of diabetes is seen as a medical problem but that the treatment involves lifestyle management in its widest sense - surely an OT role? Need to think how I am going to move forward with this. Are these themes that will just emerge from my study? How does the way you set up the research impact on the way these are explored? (November 2012).*



**Figure 5 Building Meanings**

*The words - creativity, meaning, purpose, choice, opportunity, balance, challenges, growth, and potential - were written in my research diary in the early days of thinking about OT and health and wellbeing. I transferred them onto the layers of paper using a transparency and water technique, and then built up and stitched together the layers of paper. For me they represent layers of meaning which interact with and depend on each other and came to represent the layers in the study. They are bounded by the method of enquiry but the different boundaries represent different techniques to allow for more than one viewpoint and to reveal the depth of meaning. The words are significant terms in the occupational therapy lexicon and signify areas which need exploration. The butterfly suggests an awareness of not being reduced by the methodology - of being allowed to explore and fly free - while the buttons represent the necessity of also being grounded in the data.*

## **3.0 Diabetes**

### **3.1 Chapter Outline**

This chapter discusses the nature of diabetes, statistics and trends in the UK and beliefs about the current impact of diabetes on the UK health service. It examines current literature on approaches to diabetes self management through education and care planning, discussing non compliance, barriers, outcomes and sustainability. There will be links with subsequent chapters on occupational therapy, public health and health promotion and metaphor.

### **3.2 Diabetes**

Diabetes is a complex condition in which blood glucose levels are too high because the body cannot absorb it properly (International Diabetes Federation (IDF), 2013a). There are three main types: type 1, type 2 and gestational diabetes. Type 1, thought to be as the result of an auto immune process (IDF, 2013b), develops where the body cannot produce insulin, required to help glucose enter the cells where it is used as fuel. This is due to the destruction of insulin-producing cells in the pancreas (Diabetes UK, 2012a). Type 2 develops when the body does not make enough insulin or the insulin does not work properly (Diabetes UK, 2012a). It can go unnoticed and thus undiagnosed for many years with resultant long term damage (IDF, 2013a). Gestational diabetes, where the mother develops resistance to insulin can, if untreated, lead to health problems for both the baby and the mother (IDF, 2013a). In addition it increases the risk of type 2 diabetes developing later on by 7% (Bellamy et al, 2009; IDF,

2013b). In the UK gestational diabetes affects approximately 1 in 5 of all pregnancies (Cundy et al, 2014).

Treatment in type 1 involves insulin therapy and in type 2 may require medication to lower blood glucose levels. Both type 1 and type 2 require monitoring of blood glucose levels (HbA<sub>1c</sub>), blood pressure and cholesterol, collectively known as metabolic control, in order to prevent complications of cardiovascular, kidney and eye disease, and to reduce the risk of amputation and neuropathy (Diabetes UK, 2014b). Poorly controlled diabetes is also linked with depression (Lustman and Clouse, 2005), anxiety, phobias and eating disorders (Diabetes UK, 2014b). Globally people with diabetes are two times more likely to have depression than those without (Mommersteeg et al, 2013). In addition people with depression have a 60% increased risk in turn of developing type 2 diabetes (Mezuk et al, 2008). All of these negative emotions can make adherence to healthcare recommendations or changes to lifestyle difficult and thus impact on self management (Skinner, 2004).

Pre-diabetes is a borderline condition, characterised by higher than normal blood glucose levels, but not yet high enough to be diagnosed as diabetes (Mainous III et al, 2014). In the UK there is some debate over whether pre-diabetes should be considered as a separate condition (Diabetes UK, 2012b; National Institute for Clinical Excellence (NICE), 2011). However it is recommended that to prevent the development of type 2 diabetes, early intervention is essential (Diabetes UK, 2014c; Narayan et al, 2002; NICE, 2011; Public Health England, 2015).

### **3.3 Diabetes Incidence and Costs in the UK**

Worldwide there are an estimated 382 million people with diabetes (IDF, 2013b). Based on modelling and statistics of the proportion of the current UK population, Diabetes UK estimate that there are 3.8 million people diagnosed with diabetes in the UK and an estimated further 630,000 who may not be aware that they have this condition (Diabetes UK, 2014a). 90% of people with diabetes have type 2 diabetes (Health and Social Care Information Centre (HSCIC), 2012). Additionally an estimated seven million people in the UK have pre-diabetes (Diabetes UK, 2009). Based on a diabetes prevalence model, it is predicted that 5 million people in the UK will have diabetes by 2025, most of these Type 2 diabetes, due in part to an ageing population (Diabetes UK, 2014a).

In the current climate of increased healthcare costs generally with competing claims on scarce resources, the impact of diabetes on health and social care costs is significant, with considerable personal impact for the person with diabetes and their family. Diabetes UK (2014a) estimates that diabetes costs the NHS £10 billion each year, approximately 10% of the NHS budget, and 80% of these costs are due to the complications of diabetes. There are currently no statistics to estimate the cost of diabetes to social care, but one in four residents in care homes has diabetes (Sinclair et al, 2001). In addition it is estimated that diabetes costs nearly £9 billion in reduced productivity at work (Hex et al, 2012). The National Audit Office (2012) estimates that the NHS could save £170 million a year with better understanding and management of diabetes.

### **3.4 Approaches to Diabetes**

Approaches to diabetes come under the three areas of health improvement, health protection and health services. These three domains of public health are discussed further in Chapter 5.2.1. In terms of health improvement and protection type 2 diabetes has been linked to the wider societal environment which is believed to have led to physical inactivity, sedentary behaviour and unhealthy diets (Knowler et al, 1995). It has been argued therefore that intervention should be aimed at the particular lifestyle determinants of health to prevent diabetes developing (Diabetes UK, 2012b; Rose, 1993). In relation to health services, current approaches to the long term treatment of diabetes include education, self management and lifestyle change to improve outcomes and ultimately reduce health costs (NICE, 2003). These three approaches will be discussed below.

#### **3.4.1 Education**

Education is based around individual health beliefs, dietary advice, facilitating behaviour change, improving quality of life, optimising metabolic control (in terms of managing blood sugar levels ( $HbA_{1c}$ ), blood pressure and cholesterol levels), addressing cardiovascular risk factors and reducing depression (National Collaborating Centre for Chronic Conditions (NCCCC), 2008). DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) is one approach being rolled out across the country to help those with type 2 diabetes to understand and self-manage their condition (Davies et al, 2008;



Gillett et al, 2010). The Expert Patients Programme (EPP) is another structured education course which in diabetes has been shown to increase knowledge and skills in diabetes self-management (Deakin et al, 2006; Donaldson, 2003). DAFNE (Dose Adjustment for Normal Eating) training for those with type 1 diabetes is designed to allow a flexible approach to eating while also ensuring tight control of glucose levels through self-management of background and meal-related insulin (Heller, 2009).

The Department of Health and NICE guidelines all promote the use of structured education. However, both acknowledge that there is insufficient evidence to recommend a specific type, setting or number of sessions (DOH, 2006a, NICE, 2003). The National Audit Report 2012-2013 acknowledges that only 3.9% of newly diagnosed people with type 1 and 16.7% of people with type 2 diabetes nationally were recorded as being offered structured education while evidence of people actually attending is also low – 0.9% type 1 and 3.6% for type 2. (HSCIC, 2014). Clark and Hampson (2003) found that people with type 2 diabetes did not regard either their condition or value tight glycaemic control as seriously as the healthcare professionals.

One reason for people with diabetes not sharing the same concerns as healthcare professionals may be due to variation in diabetes services. The National Diabetes Audit 2009-10 revealed that less than one in five people with diabetes were achieving optimal metabolic control and that 15% were not actually being tested (National Audit Office, 2012). It showed wide variations in the treatment

available in the NHS to meet the recommended standards of care. This included variation in standards of diabetes education and diabetes training for NHS staff (National Audit Office, 2012). In addition health literacy is seen as influencing how successfully people process the information they are given to make informed choices in relation to the complexity of their diabetes (Sayah and Williams, 2012).

### **3.4.2 Self Management of Diabetes**

People with diabetes are estimated to have only three hours contact with healthcare professionals per year and thus there is a strong focus on self management (DOH, 2005d). The background to self management (or self care, as it is also named) is discussed further in Chapter 5. A useful definition of self management is *“the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”* (Barlow et al, 2002, p.178). Health policy is directed towards individual responsibility where people with diabetes manage the remaining 8757 hours per year using advice and support given by healthcare professionals in those three hours (DOH, 2005d). There are clearly risks to this approach in terms of the appropriateness of the contact time, the ability of the individual to understand advice, access to resources and individual choice (DOH, 2005d). The following sections examine these risks in more detail.

The National Service Framework for Diabetes (DOH, 2001) established twelve standards to drive the quality of diabetes care. Standard 3 in particular focuses on encouraging people with diabetes to take an active role in self care through

the provision of care planning. This is defined as *“a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed”* (DOH, 2006b, p.11). Based on the “disease-illness model” (Stewart and Roter, 1989) care planning offers two parallel processes of the illness framework (the person’s agenda and unique experience of diabetes) plus the disease framework (the ‘doctor’s’ agenda) and integrates these two frameworks for shared understanding and decision-making. Being based on disease, however, it can ignore the broader self management of the impact of diabetes on the individual’s life, values and priorities, as can be seen in the summary of the self-management literature below.

There is much debate about the efficacy of self management as reflected in the literature. For example, in their systematic review of self-management interventions for type 2 diabetes between 2000 and 2010, Heinrich et al (2010) concluded that multi-component self management interventions were effective in changing dietary behaviour and diabetes specific quality of life, but that the interactions between the different components were not understood in terms of managing change in lifestyle. They concluded that collaborative learning improved understanding of diabetes and some self-management behaviours. There was however no discussion about the long term health benefits or health costs associated with this approach. Previously Norris et al (2001) had systematically reviewed the effectiveness of self-management training in randomised controlled trials (published between 1980 and 1999) and concluded that the evidence supported its effectiveness, at least in the short term, but that

further research was required to look at the sustained benefits on glycaemic control, cardiovascular disease risk factors and quality of life. In addition there is an argument to suggest that low mood with diabetes can have a major impact on individuals' ability to make lifestyle changes and that this would need to be taken into consideration when deciding on the components of self-management techniques (van der Feltz-Cornelis, 2011).

It is not clear which outcome measures should be used to determine improvements in diabetes control. Many of the studies focus on biochemical tests such as blood glucose control (reduction in HbA1c) (Brackenridge and Swenson, 2004), body mass index, high density lipo-protein and total cholesterol, systolic and diastolic blood pressure (Gilis-Januszewska et al, 2011; Matthews, 2007). Other studies suggest that outcomes should be in terms of self reported self-management behaviours, self efficacy (Atak et al, 2008; King et al, 2010); health related quality of life, patient satisfaction and adherence to treatment (Barbosa et al, 2011); or patient reported psychosocial and behavioural measures (Glasgow et al, 2008). In addition there are calls for robust, high quality research to assess the theoretical principles of behaviour modification, motivational interviewing, cognitive behaviour therapy, goal setting and coping skills in managing diabetes, especially in terms of applicability and implementation (Ramsay et al, 2010).

It is generally agreed that self management is complex, requiring technical skills in terms of testing and medication plus problem solving skills to make

adjustments and manage potential barriers (Hill-Briggs, 2003). Barriers can be biological, psychosocial or economic related to fitting self management into individual lifestyles (Hall et al, 2002). Despite the best intentions of the health service in providing education, advice and targets in terms of metabolic control, the reality of the situation is that many people with diabetes are either unable or unwilling to take this advice (Funnell and Anderson, 2004). Partly this could be due to prescriptive care plans not fitting in with a person's particular priorities in terms of their lifestyle, goals and resources and/or readiness for change (Funnell and Anderson, 2004; The Health Foundation, 2013). Additionally attempting to manage diabetes can be seen as impacting on self identity. Gomersall et al (2011) concluded that self-management operates on two levels: internally in terms of the self and externally in terms of cultural resources, including interactions with healthcare professionals. They argue that assimilating the amount and complexity of information about diabetes can be seen as a threat to a person's sense of self. Other issues with self management include difficulties that some people face in handling the responsibility of self-management (Minet et al, 2011).

One approach to self management in type 2 diabetes is the process of empowerment whereby people with diabetes are facilitated to make their own choices and goals in terms of nutrition, weight loss and physical activity (Anderson et al, 1995; Anderson and Funnell, 2010). While this can be viewed by healthcare professionals as a way to increase compliance with recommendations, Anderson and Funnell (2010) explain that it is instead an approach to help people

take charge of their management and make their own informed decisions. Inevitably this means that at times informed choices will not always match professional recommendations, which can cause issues when healthcare professionals “*cling to professional dominance*” and inhibit their clients’ decisions (Paterson, 2001, p.579). In the worst case scenario people’s own in-depth knowledge and subsequent self-management is seen as non compliance by less knowledgeable professionals (Snow et al, 2013).

Overall, although self management is strongly influenced by healthcare professional recommendations, it is deeply embedded in the individual’s unique life situation (Moser et al, 2008) and is not just about compliance with medical recommendations. This being the case, a focus on individual life situations would seem to be the way forward (Audulv et al, 2012; Ingadottir and Halldorsdottir, 2008).

### **3.4.3 Lifestyle Change**

The National Institute for Health and Clinical Excellence (NICE) guidance advises lifestyle change for those with a high risk of developing type 2 diabetes (NICE, 2012).

Most lifestyle interventions cover diet, exercise and behaviour modification (Diabetes Prevention Program Research Group, 2002). Some, such as the Diabetes in Europe: Prevention using Lifestyle, physical Activity and Nutritional intervention (DE-PLAN) focus on very specific goals: increased physical activity, weight loss, increased consumption of fibre, fruit and vegetables, reduced

consumption of total and saturated fats (Gilis-Januszezewska et al, 2011). Physical activity takes the form of aqua-aerobics and gym sessions (DE-PLAN) or, as in the Finnish Diabetes Prevention Study, circuit training plus advice on increasing physical activity overall (Lindstrom et al, 2003). Intervention takes the form of structured education group discussions, self monitoring and goal setting (Absetz et al, 2009). Systematic reviews of the lifestyle intervention conclude that as an intervention it appears to be as effective as drug treatment (Gillies et al, 2007).

Although aimed at reducing risk factors, by focussing on weight loss and increase in physical activity, lifestyle intervention appears to have a very narrow focus with not much evidence of managing this in the context of an individual's life circumstances. As Gillies et al (2007) argue, the key to successful lifestyle intervention is compliance. This is potentially at odds with the empowerment model discussed above and it would seem that rather than focussing on compliance strategies to manage a lifestyle that many people would not necessarily choose, an approach that starts with the individual's lifestyle might potentially be more effective. Ingadottir and Halldorsdottir (2008) conclude that managing diabetes is a constant balance between the prescribed regimen (medical recommendations) and the well-being of living a normal life.

Evidence suggests that, despite educational programmes, many people with diabetes fail to adhere to advice on self management and there are many barriers to successfully incorporating this into individual lifestyles (Mulvaney, 2009, Nagelkerk et al, 2006). Misconceptions have been identified between

empowering people to take control of diabetes daily care and expecting compliance with metabolic control (Anderson and Funnell, 2010; Paterson, 2001). Overall diabetes management requires a complex interaction between medication administration, self monitoring, diet, exercise, and consultation with healthcare professionals (Moser et al, 2008).

### **3.5 The Lived Experience of Diabetes**

The majority of the literature on diabetes is focussed on metabolic control and the ways in which individuals can be supported to manage this. However, as can be seen from the sections above, it is important to focus on the individual experience of actually living with diabetes. Research on the lived experience of diabetes tends to be found in nursing journals where the themes focus on how people self manage and gain control (Edwall et al, 2008; Handley et al, 2010). Factors that help to achieve control include personal belief, support from friends and family, and interaction with healthcare professionals (Edwall et al, 2008; Handley et al, 2010). Although it appears that the participants in these studies adapted to and maintained control over their diabetes, the authors acknowledge the difficulties of managing diabetes on a daily basis. Difficulties include the psychological burden of diabetes, sometimes dealt with by reality avoidance (Gillibrand and Flynn, 2001) and imposed powerlessness (Livingstone et al, 2011) especially in relation to living with diabetes-related amputation. Overall, there is a paucity of information on the lived experience of pre-diabetes. Andersson et al (2008) studied the meaning of living with pre-diabetes and concluded that this was conceptualised as a turning point where participants were caught between



possibilities (of changing lifestyle to prevent development of type 2 diabetes) and obstacles (developing the condition). The literature suggests that it is imperative for healthcare professionals to understand the personal issues and reality of living with diabetes in order to better engage and enable people to self manage (Handley et al, 2010).

One area that is starting to be recognised as having an impact on how people experience living with diabetes is that of stigma (Browne et al, 2013; Browne et al, 2014; Schabert et al, 2013). Negative and oversimplified views of diabetes, especially for those with type 2 diabetes, can be experienced from friends, society in general, the media and even healthcare professionals (Huber et al, 2015). Those with type 2 diabetes report feeling blamed for causing their condition and experience restricted opportunities in life (Browne et al, 2013). Those with type 1 diabetes have reported experiencing stigma-by-association with type 2 diabetes as well as specific instances of blame around blood sugar control, or being suspected of taking drugs when injecting insulin (Browne et al, 2014). These negative judgements can lead to emotional distress and feelings of exclusion, guilt, rejection, shame and blame, all of which can make diabetes harder to manage effectively (Browne et al, 2013).

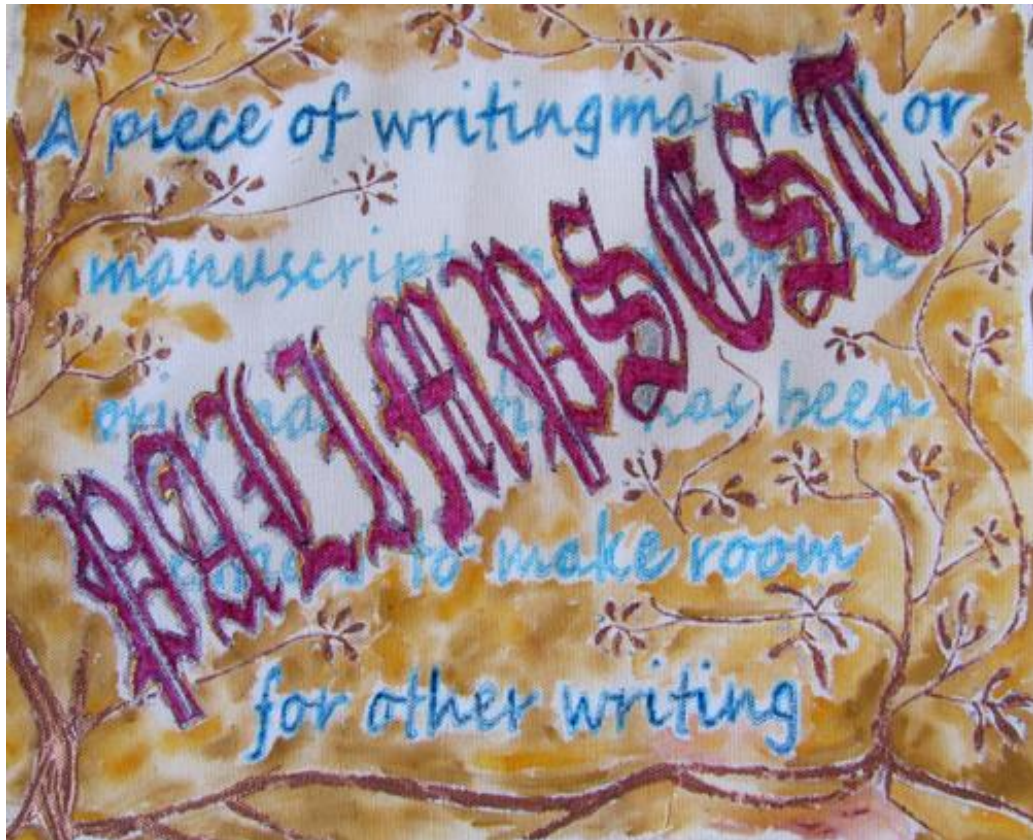
### **3.6 Summary**

This section has reviewed the nature of diabetes and its current impact on the UK health service. It has examined the literature on approaches to managing diabetes through education, lifestyle change and self management and reviewed

the lived experience of diabetes. It is apparent from this review that diabetes is a complex condition to manage, that it impacts on a person's sense of self, values and routines. Although not specifically researched in this context, it seems apparent that it is experienced in the context of an individual's life context and impacts on and is impacted by people's occupations. Changing lifestyles is seen as one of the cornerstones of managing diabetes and it would appear that occupational therapists should be well placed to offer understanding and expertise in this area. This will be discussed more fully in the next chapter on occupational therapy. The following reflection considers the impact of professional stance on research findings.

***Reflection on the diabetes literature:***

*I was thinking over my options for the focus re the diabetes findings and suddenly wondered whether the results of research depend on your professional hat and then wondered why I hadn't thought of that before. Most of the research on the lived experience of diabetes comes from nursing and it invariably follows the themes of chaos at first diagnosis, getting control and maintaining control. When the themes from my own participants didn't seem to fit that pattern I was concerned - whether my analysis was incorrect, whether it mattered at what stage in people's experience of diabetes you did the research, whether I hadn't asked the right questions etc. But then this morning I thought that maybe, because the nurse focus might be more biomedically based and looking at metabolic control then that's what they 'saw' whereas as an OT I have been (subconsciously or otherwise) looking at the wider occupational picture so not seeing the chaos to control continuum? (Sept 2013)*



**Figure 6 Palimpsest**

*The word palimpsest means 'a piece of writing material or manuscript on which the original writing has been effaced to make room for other writing'. This represents how my understanding and knowledge of occupational therapy has been 'over written' by what I have learned through the research study.*

## **4.0 Occupational Therapy**

### **4.1 Chapter Outline**

This chapter of the literature review is focussed on occupational therapy. It begins by exploring definitions of occupational therapy, occupation, and wellbeing. It examines the role of occupational science in understanding occupation; the core theories and philosophy of the profession; language and metaphor; occupational therapy's role in medicine and occupational perspective on health. In addition this chapter explores occupational therapy's role in health promotion and its place in the current prevention and management of diabetes. It is important to point out that the views discussed here are placed within the Western world view and beliefs in which the research took place (Hammell, 2009). It is acknowledged that these may be different to other cultures and contexts (Hammell, 2011).

### **4.2 Definitions of Occupational Therapy**

There has been much debate over many decades in the occupational therapy profession about definitions of practice and the inability of occupational therapists to define what it is that they do (Creek, 1998; Creek, 2009; Turner, 2011; Wilding, 2010; Yerxa, 1967). Wilding (2010, p.12) suggests that the challenges in defining occupational therapy have come about through therapists using "*over-inclusive*" definitions to explain the diversity and complexity of the profession. Creek (1998) states that it is to do with uncertainty about professional identity, role and function. She argues that partly this is to do with

the complexity of explaining the concept of health and wellbeing through the medium of occupation and partly that practitioners use key concepts, such as occupation and activity, interchangeably without clear definitions (Creek, 1998). These issues are in evidence more recently where it is still acknowledged that we are unknown as a profession and that others do not understand our role (Ashby et al, 2015; Polatajko, 2012).

However it is important to make some attempt at defining the key concepts in order to position occupational therapy in the arena of public health in relation to diabetes. The following definitions are from a review of the literature relevant to the study.

#### **4.2.1 Occupational Therapy**

The central philosophy of occupational therapy is a belief in the impact of occupation on health and wellbeing (COT, 2014) and the practice that therapists are “*experts in occupation*” (Wilding, 2010, p.12). It is believed that occupational therapy is necessary when individuals experience challenges in their occupations of everyday living (Polatajko, 2007). Of the many definitions available, that of the World Federation of Occupational Therapists (WFOT) (2012) has been chosen to describe occupational therapy. It is a wide and encompassing definition which explains both the essence of the philosophy and the practice of the profession: “*Occupational therapy is a client-centred health profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with*

*people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.” (WFOT, 2012).*

#### **4.2.2 Occupation and occupational science**

Although occupation is a central concept of occupational therapy, defining what it is has also been problematic (Molineux, 2010). Occupational science, as a separate but aligned area of study, was developed to make sense of the function and meaning of human occupation (Zemke and Clark, 1996) and to bring occupational therapy back to its core roots (Molineux, 2004). In common usage occupation is often assumed to be related to work and thus the profession of occupational therapy is often confused with occupational health (Creek, 2010). Within the profession it is most often defined in terms of tasks or daily activities (Creek, 2010). In 2004, the College of Occupational Therapists (COT) defined occupation as *“an activity or group of activities that engages a person in everyday life, has personal meaning and provides structure to time”* (COT, 2004, p.2). In the same year, Watson (2004, p.3) described occupation as *“the ordinary and extraordinary things that people do everyday”*. She suggested that occupation is *“central to the way we all live our lives – what we are, who we become and how we achieve our dreams and aspirations”* (Watson, 2004, p.3). The European definition adopted by the European Network of Occupational Therapy in Higher Education (ENOTHE) working group describes occupation as *“a group of activities that has personal and sociocultural meaning, is named within a culture and supports participation in society. Occupations can be categorized as self-care,*

*productivity and/or leisure.”* (Creek 2010, p.68). ENOTHE explains that occupations are *“the performance of activities that we observe”* (Creek, 2010, p.68).

As ENOTHE suggests, occupation is often separated by occupational therapists into the domains of self care, leisure and work/productivity. These domains have their own history of definition debate but for simplicity the following descriptions are applied. Self care has long been viewed as the personal care tasks of taking care of one’s body (Christiansen and Baum, 1997). This includes personal hygiene, dressing, meal preparation and eating, shopping, money management, sleeping, sexual expression, mobility and travel (van Huet et al 2010, p.342). Leisure is traditionally seen as non-work time where choice is made as to which occupations one engages in (Sellar and Stanley, 2010). It is often linked to recreation and is seen as both an activity and a subjective experience (Sellar and Stanley, 2010). Work is a concept that is used interchangeably with productivity (Reed and Sanderson, 1999). It is seen as both paid employment and as unpaid productive occupations (Cook and Lukersmith, 2010). Unpaid work could include such occupations as development of knowledge, housework, volunteering, and caring for others (Reed and Sanderson, 1999). It is clear that occupations do not necessarily fit into just one category (Creek, 2010) although models of occupation generally separate occupation into these three specific categories (Hammell, 2014). There has been criticism of this division, notably that it is too simplistic and that there can be many overlaps (Pierce, 2001; Hammell, 2009). What one

person defines as leisure (eg sports) could constitute work for another (Reed and Sanderson, 1999).

This concern that occupational therapists have been viewing occupation too simplistically led to the more formal study of occupation through occupational science. Zemke and Clark, two notable early occupational scientists, were concerned about *“untangling the complexity of occupation and gaining a sense of its centrality in the framework of human lives”* (Zemke and Clark, 1996, p.xi). Hocking and Wright-St Clair (2011) define occupational science as the study of what people do, while Clark and Lawlor (2009) highlight the centrality of occupation in people’s lives with a specific focus on health, wellbeing and participation. The value of occupational science in terms of understanding occupation and its relationship to health and wellbeing enables occupational therapy to focus on occupation rather than dysfunction and provides support for what occupational therapists do in practice (Molineux and Whiteford, 2006). Above all, understanding the nature of occupation requires consideration of the person, the occupation, the context in which it takes place and the relationship between those three elements (Polatajko, 2011).

#### **4.2.4 Well-being**

Wellbeing, like the concepts above, is seen as intangible, sometimes associated with prosperity and happiness, and not just health (Wilcock, 1998). For occupational therapists a sense of health and wellbeing comes from *“being in tune with our ‘occupational’ species nature”* (Wilcock, 1998, p.123); from successfully carrying out valued activities (Dige, 2009); and experiencing the



satisfaction and fulfilment of occupation (Doble and Santha, 2008). There is no consensus on a fundamental list of human needs necessary for wellbeing but it includes such things as individual growth, intrinsic motivation and quality of experience (Christiansen and Matuska, 2006). Hammell (2010) contests the idea of well-being as an individual experience and argues that it includes interdependence and mutual responsibility. It is likely that this will vary from person to person and in different sociocultural contexts (Kitayama et al, 2010).

## **4.3 Theory of Occupational Therapy**

### **4.3.1 Core Beliefs of Occupational Therapy**

While it is not intended to provide a lengthy history of occupational therapy, it appears essential to explore the core beliefs in order to conceptualise the ways in which occupational therapy might be applied to helping people to manage their diabetes, either specifically in terms of self management or more widely in terms of general health and wellbeing.

To understand the core beliefs of the profession it is necessary to go back to the views of some of the original theorists. Wilcock (2001) suggests that not having an understanding of the long history of occupation and health and wellbeing can result in occupational therapy practice based on and limited to more recent policy and uses a metaphor to describe such practice as a *“rudderless ship without an anchor in an uncharted sea”* (Wilcock 2001, p.4). Wilcock argues that understanding the core beliefs *“may help provide the courage to leave port,*

*and supply a rudder and an anchor for the exciting journey ahead”* (Wilcock, 2001, p.4).

Wilcock (2001) states that the idea of occupation for health stems back to early civilisation, where occupations of day to day living provided the means of survival, prevented illness and maintained health. Wilcock (2001) emphasises the history of occupation and health throughout history, from the Greek multi-purpose gymnasia through to the medieval Regimen Sanitatis and on to the social reformers of the nineteenth century who developed public, occupational and social health practices. In the early asylums occupation became a major part of moral treatment for the health and well-being of the residents and later it was used for economic as well as therapeutic benefits (Wilcock, 2002). During the 1<sup>st</sup> and 2<sup>nd</sup> world wars occupational therapists were active in working with wounded soldiers to promote health and wellbeing in occupational workshops addressing mental health and physical issues (Wilcock, 2002).

In 1961, Mary Reilly explored the worth of occupational therapy as being *“one of the great ideas of 20<sup>th</sup> century medicine”* (Reilly, 1962, p.1). She used the metaphor of examining the roots of the profession to consider what growth had emerged. The hypothesis at those roots was *“that man, through the use of his hands as they are energised by mind and will, can influence the state of his own health”* (Reilly, 1962, p.2). Reilly acknowledged that at the time, the profession was in a state of flux and that she was espousing the American philosophy of the need to be occupied productively and creatively, in order for the profession to be

recognised in the field of medicine. She identified the principle that people need to control their environments to alter and improve them and that where that need was blocked by disease or injury, the result was dysfunction and unhappiness (Reilly, 1962). At that time she promoted the need for understanding sensory-motor systems, the acquisition of skill, and understanding of problem-solving and creativity. With this knowledge occupational therapists could help people to achieve health through productive occupation (Reilly, 1962).

The view that a person could improve their health through the medium of occupation became embedded as a core belief and the profession continued to be aligned with medicine in both the UK and USA (Yerxa, 1992; Turner et al, 2010). This is explored further in section 4.5.1 and is a necessary analysis to see where the core skills of occupational therapy may have become subsumed by medicine but also to consider where occupational therapy could fit into medical health policy in the future.

In terms of developing the core beliefs of occupational therapy into their current manifestation (see Table 1, p.45), beliefs about the nature of occupation and health were promoted in terms of self-actualisation (Yerxa, 1967). Here it was believed that occupational therapy should be based on exposing clients to a range of occupational opportunities with the client making the choice. Occupations were seen as the source of motivation to enable people to determine their "*being*" (Yerxa, 1967, p.8). Ideas were developed recognising

the demands of the environment (Yerxa, 1994) and about ensuring a balance of occupations for health and wellbeing (Christiansen, 1996).

The concept of occupation widened to include not only the 'doing' of occupation but also as the means through which people express and understand themselves (Christiansen, 1999; Laliberte-Rudman, 2002). Ill health had the potential to impact on that sense of self where people were unable to continue with habitual occupations (Charmaz, 1983; Christiansen, 1999). Christiansen (1999) argued that occupational therapy could contribute to health and wellbeing by addressing those identity challenges through occupation.

Occupational science, by explicating the relationship between occupation and health, has enabled occupational therapy philosophy to be directed towards enabling positive life experiences through meaningful participation (Hildenbrand and Lamb, 2013). To achieve this, it is believed that a person requires competence to participate in a range and balance of occupations, according to their needs and circumstances (Duncan, 2011). This competence depends on the interaction between the person, the particular occupation and the environment (Duncan, 2011). Doble and Santha (2008) argue that focussing on individual need for accomplishment, agency, companionship, pleasure and renewal will lead to occupational wellbeing.

The current core beliefs of occupational therapy are summarised in Table 1.

<b>OCCUPATION</b> <ul style="list-style-type: none"> <li>• Gives meaning to life</li> <li>• Organises behaviour</li> <li>• Develops and changes across the lifespan</li> <li>• Shapes and is shaped by environments</li> <li>• Has therapeutic value</li> </ul>
<b>PERSON</b> <ul style="list-style-type: none"> <li>• Is an occupational being</li> <li>• Has right to self-determination and to make choices about life</li> <li>• Has ability to participate in occupations</li> <li>• Has potential to change</li> <li>• Shapes and is shaped by environments</li> </ul>
<b>ENVIRONMENT</b> <ul style="list-style-type: none"> <li>• Includes physical, social, cultural, political and economic elements</li> <li>• Influences choice, satisfaction, performance and organisation of occupations</li> </ul>

**Table 1 Core Beliefs of Occupational Therapy**

(Adapted from Canadian Association of Occupational Therapists, 2007)

#### 4.3.2 Core Skills of Occupational Therapy

It is recognised that physical, psychological, spiritual, cultural and political factors can all influence participation in occupation (Whiteford et al, 2000). The occupational therapist has a number of core skills built around this understanding and of the complex interaction between the person, the occupation and the environment (Creek, 2003). Although quite old now, these core skills as put together by Creek (2003) are those that are still quoted by COT (2013). They are summarised in Table 2.

<b>CORE SKILLS OF OCCUPATIONAL THERAPISTS:</b>
<ul style="list-style-type: none"> <li>• Collaboration with the client</li> <li>• Assessment</li> <li>• Enablement</li> <li>• Problem solving</li> <li>• Using activity as a therapeutic tool</li> <li>• Groupwork</li> <li>• Environmental adaptation</li> </ul>

**Table 2 Core Skills of the Occupational Therapist (Creek, 2003)**

It is evident that these core skills could apply to a number of different health professions and more recently they have been viewed as limited to practice within the health and social care systems (Pollard et al, 2008). Within occupational science, the study of occupation has moved towards consideration of power and justice and the notion of occupation as being socially and politically situated (Kronenberg et al, 2005). Concepts such as occupational justice, deprivation and dysfunction (Pollard et al, 2008; Whiteford 2000) have been suggested as a means by which the core skills of occupational therapists should be expanded to address social inequity worldwide through occupation (Kronenberg et al, 2005).

#### **4.3.3 Occupational Therapy Process**

Occupational therapy intervention follows a series of steps in which the therapist works with the individual to identify any issues or problems with participation in occupation and then implements a treatment programme to address these issues (Creek, 2003; Duncan, 2011). The process includes assessment, formulation of problem or issue, action planning (including setting of goals), reflection and potential revision of the plan, plus measuring outcomes (Creek, 2003). As Duncan (2011) points out, while its focus on occupational participation is unique, the process of problem solving and finding solutions is one that many healthcare professionals use.

#### **4.3.4 Occupational Therapy Models**

There are many theoretical models used to explain the complex interaction of the person, the occupation and the environment such as the Canadian Model of

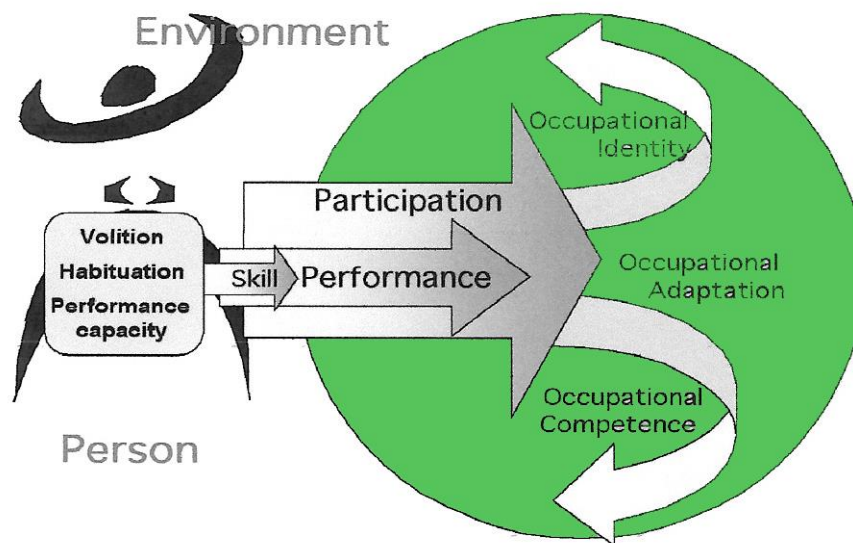
Occupational Performance and Engagement (Polatajko, Townsend and Craik, 2007); Person-Environment-Occupation Model (Law et al, 1996); Model of Human Occupation (Kielhofner, 2008); Kawa (River) Model (Iwama, 2005). Models help to understand people as occupational beings, provide a focus for intervention and assist with clinical reasoning (Owen et al, 2014).

Although occupation-focused models are often not used due to therapists' lack of understanding of the theoretical concepts (Ikiugu, 2010), one of the most widely used models in practice and in research is the Model of Human Occupation (Haglund et al, 2000; Law and McColl, 1989; Lee et al, 2008; Lee, 2010; Lee et al, 2012). In my own case, training in the use of the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS) (Forsyth et al, 2006), one of the assessment tools of the Model of Human Occupation (MOHO), led to developing this model into practice. Further training on the use of MOHO through the UK Centre for Outcomes Research and Education (UKCORE) programme (Forsyth et al, 2005), in the manner described by Wimpenny et al (2010), consolidated this implementation.

A brief introduction to this model is given below to illustrate occupational therapy core beliefs concerning a person and their occupational participation.

The Model of Human Occupation (MOHO) grew out of the need to understand *"the nature of occupation in human life and its role in health and illness"* (Forsyth and Kielhofner, 2003, p.47). Its concepts address:

- Motivation for occupation
- Routine patterning of occupational behaviour
- Nature of skilled performance
- Influence of environment on occupation



**Figure 7 The Model of Human Occupation (Parkinson et al, 2004, p.6).**

Reproduced with the permission of the MOHO Clearing House, (email correspondence with Renee Taylor 25/5/15)

Figure 7 identifies the parts of this model. Within the model Kielhofner (2008) summarises three components of the person: volition, habituation and performance capacity. Volition is further divided into personal causation, values and interests, which motivate what people choose to do, which would appear to be particularly important to the concept of self-management. Habituation includes the habits and roles that shape patterns or routines of occupation. Performance capacity includes the physical and mental abilities plus subjective



experience that underlie occupational participation. In addition the physical and social environments provide opportunities, resources, demands and constraints on people's abilities to engage in occupations (Kielhofner, 2008). The individual's skills and performance allow occupational participation. Participation helps to create an occupational identity. Occupational competence is the degree to which this occupational identity is sustained while occupational adaptation is the longer term construction of this identity through occupational competence (Parkinson et al, 2004).

The model is useful to examine life roles (Christiansen and Matuska, 2006). By examining people's roles (eg worker, spouse, student, parent) occupational therapists can discover how different combinations of roles result in varying demands and resultant stress; or how managing valuable roles can lead to wellbeing (Matuska and Christiansen, 2008). It is recognised that performance of occupations is influenced by mood, cognition, learning and alertness (Christiansen and Matuska, 2006). In addition, models, such as the MOHO (Kielhofner 2008) can help therapists to examine environmental issues such as social/geographical isolation, economic constraint, conflict, homelessness or incarceration and their impact on occupation and health (Matuska and Christiansen, 2008). MOHO will feature further in the Theoretical Discussion, Chapter 13, as a way of conceptualising the occupation of diabetes self management.

It could be argued that a relevant model to use in keeping with the use of metaphor in this study would be that of the Kawa model (Iwama et al, 2009; Turpin and Iwama, 2011). The Kawa model uses the metaphor of the river for the life journey in which elements such as the shape of the river, rocks and driftwood represent aspects of particular circumstances of that person's life which affect the life flow (Iwama et al, 2009). Designed specifically for the need to find a culturally appropriate model for Japanese occupational therapy (Turpin and Iwama, 2011), the river is not seen as an individual's but represents a collective culture and interdependence (Iwama, 2006). It does not purport to be applicable for all cultures (Turpin and Iwama, 2011). A private conversation with Iwama at the WFOT conference in 2014 revealed a particular difference in approach between the metaphors used by participants and the Kawa. In Iwama's model the person *is* the river; for the participants in this research who used a similar metaphor (see Table 13, page 211, and table 24, page 258 ) the river was the vehicle by which they were taken on life's path but essentially they were *on* the river, representing the Western view of the individual as separate from the environment (Iwama et al, 2009). This highlights not only cultural differences but, in this study, the importance of allowing someone to use their own metaphor and to explain it in their own terms, rather than 'imposing' a metaphor for their life's journey.

#### **4.4 Occupational Therapy's Perspective on Health**

From the definition cited in Section 4.2, it can be seen that occupational therapy links health and wellbeing to participation in occupation (Creek, 2003). This view is unique in the health and care field in that the health emphasis is on performing occupations rather than absence of disease or illness (Creek, 2003; Turner, 2011; Wilcock, 2005). The occupational therapy perspective on health also leads to the belief that being unable to participate in occupations has a negative impact on health (Creek, 2003). There is emerging evidence to show that lifestyles which include occupations that address basic and universal needs and which also safeguard against stressors may help to prevent disease and promote health (Christiansen and Townsend, 2011).

However, there is not universal agreement on the claim that there is a positive relationship between occupation, well-being and health. Hammell (2009) suggests that although the perceived wisdom may be justifiable, she points out that most of the theories of occupation are proposed by western, white, middle class, able bodied theorists (Hammell, 2011) and thus cannot be assumed to be universally acceptable or credible.

Additionally, it is clear that not all occupations promote health. Occupations can include risk taking behaviours, work environments that are not healthy (Stadnyk et al, 2011); burnout or over-use injuries in children who are pushed into too many occupations (Brenner, 2007); the dark side of occupation which is anti-social, unproductive, self-damaging, deviant, criminal, illegal, harmful, addictive,

destructive to self and others (Dickie, 2009; Erlandsson, 2013; Twinley, 2013). There are also politically, religiously or socially extreme behaviours which may provide a sense of well-being and identity, purpose and creativity eg football hooliganism (Twinley, 2013) but could not necessarily be seen as health promoting. In fact part of healthcare is focussed on actually treating the consequences of misuse of occupation (Wilcock, 2007). Occupational therapists need to be aware of the potential negative impacts of certain occupations and focus instead on enabling people to make healthier choices through their occupations (Erlandsson, 2013).

## **4.5 Occupational Therapy in Healthcare and Health Promotion**

This section examines the links between occupational therapy and health promotion. To put this into context it first looks at the profession's association with medicine.

### **4.5.1 Occupational Therapy within Medicine**

Historically occupational therapy's association with medicine was for reasons of acceptance, growth, funding, status and approval (Colman, 1992; Friedland, 1998; Friedland and Silva, 2008; Turner, 2011; Wilcock, 1998; Wilcock, 2002; Yerxa, 1992) but occupational scientists believe this allegiance has resulted in what is termed a 'mechanistic approach' focussed on impairment reduction, dominated by the biomedical perspective, in which many of the core concepts

around the value of occupation have been lost (Molineux and Baptiste, 2011; Wilding and Whiteford, 2009).

In this perspective of medicine the 'high-tech' of saving lives is seen as important (see Chapter 6.3.1 on military metaphors), while rehabilitation (where occupational therapy often sits) has only a minor function and can be overlooked (Elliott, 2012; Leland et al, 2015). Many occupational therapists find themselves unable to focus on occupational performance in the rapid turnover culture of today's health services (Turcotte et al, 2015).

The paradox is that, while continuing allegiance with medicine in this way, occupational therapists maintain their own limited framework for viewing health, whereas, as can be seen in the preceding sections, the concepts of occupational science and occupational therapy allow for a much more diverse and client centred approach to individuals. Over thirty years ago Rogers (1982) suggested that, through its alliance with medicine, other professionals can often be the gatekeepers to occupational therapy referrals. These are usually only made on the basis of diagnosis, rather than occupational performance dysfunction which, in turn, continues to limit the scope of occupational therapy intervention (Rogers, 1982). The same seems to be true today where practice is seen to be undermined by the views of the profession by other healthcare professional gatekeepers (Clouston and Whitcombe, 2008).

While occupational therapy continues to exist in the world of medicine it needs to focus on the individual's illness and occupational experience as opposed to the disease or long term condition, because each person's life history and circumstances bring about different aspects of that condition (Mattingly, 1994a; Moss-Morris and Petrie, 1994). Mattingly (1994a) argues that there is a danger that occupational therapy, even based on belief that occupation can influence recovery from disease, illness, or injury, will focus on the components or aetiology of that illness eg hip replacements, acquired brain injury, stroke. Hasselkus (2011) suggests that the downside of this is that the humanness can be lost – people are identified as the illness and objectified and labelled as a clinical identity – 'a diabetic' for example – and thus identity and self are at risk.

Mattingly (1994b) suggests that another way for occupational therapists to look at ill health is to see it as an interruption in life and to go beyond a functional (physiological) assessment to understanding the person's story, life history and phenomenological meaning of illness. Hasselkus (2011, p.135), in turn, sees past the discussion of the physiological to define ill health as the *"loss of the ability to carry out familiar occupations"* where health is *"the ability to carry out one's usual daily occupations"*. Occupational therapists attempt to enable people to hold onto their occupational view of themselves and enable people to live with and find fulfilment in one's self (Hasselkus, 2011).

#### **4.5.2 Health Promotion and Occupational Therapy**

For occupational therapists it is apparent that the biomedical view and the focus of public health on epidemiology are too narrow and that the focus instead

should be on the occupational person (Hildenbrand and Lamb, 2013; Wilcock, 1998; Wilcock, 2007). In order to find its place in health promotion, therefore, occupational therapy needs to reclaim its unique focus of enabling health and wellbeing through its core assumptions, summarised by Haertl (2011, p.376) that:

- Occupation has a central role in human life
- Engagement in occupation shapes or is shaped by mind-body link and environmental influences
- Lack of occupation may contribute to poor health
- Participating in occupation may restore health and function

In this way, instead of focusing on the incidence, distribution and control of disease in public health, occupational therapy could focus on the meaning and complexities of occupation. Wilcock (1998, p.227) asserts that occupational therapy could promote healthy behaviour by *“increasing understanding of how engagement in occupation can prevent illness and promote health and wellbeing and demonstrate how political, social and technological structures facilitate or inhibit achievement of occupational satisfaction and potential”*. Relating to core values and philosophy, Wilcock (1998, p.232) suggests that the following occupational therapy skills could all be used in health promotion:

- Evaluation of occupational performance skills;
- Health education related to occupational balance;
- Symptom reduction through engagement in occupation;
- Retraining occupations of daily living;
- Environmental modification;
- Work simplification

There is already some evidence in the occupational therapy literature of health promotion focussed on energy conservation for people with Chronic Obstructive Pulmonary Disease (COPD) (Sewell et al, 2010); falls prevention (Logan et al, 2010); vocational rehabilitation (Playford et al, 2012) and engagement in occupation for well-being (Clark et al, 1997; Jackson et al, 1998). Wilcock (2007) also points out that there is much research in other fields on the benefits of occupations such as cycling, walking, play, recreation, and food preparation that occupational therapists can draw upon.

#### **4.6 Occupational Therapy and Diabetes**

Given the current policy on health promotion and the occupational therapy perspective on health, it is worth considering where occupational therapy fits into the debate on diabetes self management. Mulvaney (2009) suggests that diabetes intervention should be set within the context of an individual's life story, lifestyle change, individual resources and life influences in order to reduce barriers and promote problem solving for self-management. From the discussion above this covers many of the core concepts of the occupational therapy profession.

However a review of the literature reveals that research into occupational therapy in diabetes care is sparse, particularly in relation to managing diabetes in the context of everyday life (Pyatak, 2011a). While there is evidence regarding the effectiveness of occupational therapy in improving occupational outcomes in



long term conditions, Hand et al (2011), in their systematic review, found no studies related specifically to diabetes. Previous occupational therapy papers (from the 1970s and 80s) focus on practical occupational therapy solutions to later complications of diabetes (Andrew, 1987; Budurowich and Lofton, 1979). More recently Hwang et al (2009) identified that blood sugar and cholesterol control, foot care, and pain and fatigue management were the main areas of concern to older adults with diabetes. They concluded that the role of occupational therapy is not clearly defined to enable the incorporation of diabetes self care into daily routines. Other occupational therapy approaches have looked at specific areas of diabetes intervention such as early identification of hand dysfunction (Poole et al, 2010; Ratzon et al, 2010), treating vision loss (Cate et al, 1995), foot care (Jansen and Casteleijn, 2009) or improved medication adherence (Sanders and Van Oss, 2013). Little of this actually addresses occupational engagement except for research by Pyatak (2011b) who examined how engagement in occupation influenced young adults' ability to manage their type 1 diabetes and how self-management strategies shaped occupational participation. She concluded that there was much to learn from an occupational therapy perspective and that research should be extended to include type 2 diabetes.

Since this study was started more occupational therapy research in diabetes has been reported. Fritz (2014) examined the influence of daily routines on diabetes self management and described using photo-elicitation to explore self management behaviours in low income women with type 2 diabetes (Fritz and

Lysack, 2014). Piven Haltiwanger (2012) studied the experience of Mexican-American Elders and Mexican-American adolescents with type 2 diabetes and suggested that occupational therapists should pay more attention to spiritual, cultural and psychosocial issues of adapting to diabetes (Haltiwanger and Brutus, 2012; Haltiwanger and Galindo, 2013; Piven Haltiwanger, 2012; Piven and Duran, 2014). Pyatak et al (2015) reported on the development of a manualised occupational therapy intervention for diabetes management, in which the emphasis was on integrating self management behaviours into everyday occupations and routines. Thompson (2014) considered the occupations, habits and routines related to diabetes management and the need to develop appropriate habits and routines to support self management. It is encouraging that occupational therapists are seeing the potential for developing practice into the area of diabetes self management and it is felt that this supports and validates the current study.

As yet, however, there is little evidence currently to support the role of occupational therapy in improving diabetes care in the UK. Other AHPs such as physiotherapy, dieticians, orthotists, podiatrists and orthoptists are noted for intervention points in diabetes prevention, assessment, treatment, rehabilitation, re-ablement and long term gain with research outcomes and case studies to support their intervention (NHS London, 2012). Occupational therapy is mentioned in terms of re-ablement, providing vocational advice, equipment, home adaptations, lifestyle redesign for obesity, and falls prevention but there is no evidence cited to support this role (NHS London, 2012).

It is interesting, however, that other professions have noted the impact of occupation on a person's management of diabetes. Thorne and Paterson (2001), from the nursing profession, give many examples such as a participant engaging in the occupation of quilting and trying to work out how much insulin to take according to whether they sit all evening or have to move around to collect materials. Another participant discusses the need to work out insulin levels when going to the pub and another notices how his golf swing is affected by low sugar levels (Thorne and Paterson, 2001). Additionally participants discuss the impact of medication regimes on their routines and habits, and the guilt they feel if they do not stick to a particularly regimented day (Thorne and Paterson, 2001). The implications of this for the researchers were considered from a medication point of view but a focus on the occupational perspective would seem to fit the occupational therapy approach to health and wellbeing.

#### **4.7 Occupational Therapy and Metaphor**

The final section of this review of the occupational therapy literature focuses on metaphor. As stated earlier, metaphor became an extra layer of interest as the study progressed and the literature was revisited to identify where and how metaphor was used within the profession. This is important to give insight into the metaphors used, what they mean for professional identity and what they tell us about occupational therapy practice.

A review of the occupational therapy literature reveals many metaphors related to theory and practice and not so many as an intervention. Given occupational therapy's early use of craft as a therapeutic medium (Wilcock, 2002) it is perhaps not surprising that many of these metaphors are related to *weaving* (Wood, 1995); *tapestry* (Baum, 2005; Wood, 1995); *macramé*, *knitting*, *modelling* or an *artist's studio* (Bryant, 2010); *crafting* occupational life (Kielhofner, 2008); occupation as an "*essential current*" in the "*pace and direction of life flow*" (Hasselkus, 2011, p.21). Turner (2011) uses *the iron rice bowl* as a metaphor for occupational therapists working in organisations where they cannot practice philosophical ideals and are too afraid to leave due to the comfort of institutional protection. She sees a *musical instrument* as the context in which occupational therapists work. The *instrument* can dominate the *music*, which is the belief in occupation and health and wellbeing, but Turner (2011) states that it is the *music* which is the important part. du Toit (1978, p.452) suggested, over thirty years ago, the metaphor of occupational therapy as "*a fallow land with fertile soil which is in need of careful cultivation*". This still seems apt today.

Denshire (2002, p.42) appears to be one of the few occupational therapists who has examined metaphors of practice as evidenced in her own academic writing. She came up with seven main metaphors: *integrating the firelight of creativity*; *occupational therapist as Pied Piper*; *hospital as a living being*; *hospitalisation as disruption*; *hospital as home*; *door as symbol*; and *therapy space as sacred*. She believes that they reflect her individual values and beliefs, and also that it is

important for occupational therapists to examine the symbolic level of their practice.

The language of occupational therapy focuses on health and wellbeing and the illness experience rather than the disease or condition (Moss-Morris and Petrie, 1994). In order to understand a person's particular experience of a condition such as diabetes, occupational therapists use narrative thinking (Mattingly, 1991a). This means understanding the occupational impact of the illness or condition, the symptoms and potential limitations, and seeing all of this within the context of a person's past, present and future, which Fleming (1994, p.119) describes, using the metaphor of the *"three track mind"*. This metaphor derived from her observation that occupational therapists appeared to be thinking along three tracks simultaneously while also trying to keep their therapy sessions 'on track'. Another example of narrative thinking in terms of metaphor is the Life Thread Model (Ellis-Hill et al, 2008). In this metaphor the life threads are the strands or stories that we tell about ourselves that are created and recreated throughout life and which make up a person's identity (Ellis-Hill et al, 2008).

Majnemer (2010, p.198) describes occupational therapists as helping their clients to *"balance their boat"* by participating in occupations through life's journey. She quotes from Sloman (1998) to explain this process: *"A boat cannot move very well in the water if it's unbalanced, if it's not stable. If it's a sailboat, it may be leaning over in the wind, but to proceed, it still must somehow be in equilibrium. The same is true for us"* (Sloman, 1998, p.239).

More recently Fox (2015) proposed the use of water as a metaphor for occupation. She looks at the properties of water that are relevant to the properties of occupation such as being essential to life, reflective, a conductor, without fixed form, naturally occurring and something that ebbs and flows. Fox (2015) argues that metaphors are useful tools to explain the complex concepts of occupational therapy. Youngson et al (2015) used metaphor to conceptualise the lived experience of diabetes as being a complex balancing act and demonstrated its value as a reporting method to research participants.

## **4.8 Summary**

This chapter has explored definitions of occupational therapy, occupation, and wellbeing. It has examined the core beliefs, skills, process and models of the profession and its unique perspective on health. It has looked at occupational therapy's role in medicine and health promotion and addressed where occupational therapy fits into diabetes self management. It is clear that occupational therapy has a potential role to play in enabling participation in occupation for health and wellbeing, and also in considering the impact of occupation on an individual's diabetes self management. In addition language and metaphor have been examined and found to be part of occupational therapy theory and practice. Further review of the use of metaphor in general is discussed in Chapter 6. The following reflection considers occupational therapy in relation to diabetes.

### ***Reflection on grappling with occupational therapy concepts:***

*I seem to spend many hours reading and grappling with what OT is all about. Where does the emphasis lie? What is the OT angle - the power of the occupation to get you through the practical hour by hour difficulties? So far the other OT angles seem to be around alienation and deprivation in relation to participants' dealings with healthcare staff. So from another perspective OT could be helping to highlight those issues and turn that around - so a 2 strand approach with both the healthcare staff and the way they treat people and then with the people themselves, particularly if they are going to have to make marked changes to their diet and maybe take on exercise, to find a way to positively occupy during the day. Frick and Moustakas (from Moustakas 1990, p102) reported finding their heuristic truth "the identification of a healing and growth enhancing agency within the personality". Is this what it is all about, finding the means by which people make transitions to take control, to change the way they are? And, more importantly, are we generally reluctant to do this? Is that change possible without the symbolic shift? Is a rational approach not enough? And how is this explained in OT terms? How much are identity and occupation intertwined? Will occupation enable symbolic growth experience? Do I need to go back to the research participants to explore these themes? (March 2013)*



### Figure 8 Dipping a toe in the water

Dipping a toe in the water was painted on cloth covered with gesso, using inktense pencils and a water brush. This represents the stage I'm at which is just tentatively starting the analysis. I have definitely not immersed - as this will happen after the next 2 or 3 interviews - but I'm beginning, so this was symbolised with the ripples of the water and words that I added in pencil of the things that I am going to have to start thinking about in more depth. The toe in the water is also something about my fear of the next stage. It's about not jumping straight in. I have no idea how this is going to be but I have the worries that I am sure everyone has: that the material won't be enough, that the themes won't emerge, that the subject matter is too diverse, that there'll be too much ..... but it gives me a focus to reflect on the research and acknowledge my fear.



## **5.0 Health Policy and Self Care**

### **5.1 Chapter Outline**

This chapter will discuss the current debate on public health and health promotion, and the models of care which support current UK policy. It will address the role of allied health professionals in public health and strengthen the links between occupational therapy and public health that were introduced in the previous chapter. This is to examine the context in which an occupational therapy approach to diabetes might fit into the current healthcare context in the UK.

### **5.2 Public Health and Health Promotion Definitions**

#### **5.2.1 Public Health Definitions**

There is debate about the constituents of public health and thus this section will start with some definitions. The World Health Organisation (WHO) (1998, p.3) defines public health as *“a social and political concept aimed at improving health, prolonging life and improving the quality of life among whole populations through health promotion, disease prevention and other forms of health intervention”*. As can be seen health promotion is described as a sub section of public health but, more importantly, the arena of health is seen, not just as a medical response, but as a social and political concern, which would fit with the values of occupational therapy (Kronenberg et al, 2005; Pollard et al, 2008).

The Department of Health (DOH) (2010, p.11) defines public health as *“the art and science of promoting and protecting health and wellbeing, preventing ill health and prolonging life through the organised efforts of society”*. Although, not overtly described in political terms, this definition does consider the social aspects and implies some responsibility on the part of members of society. The DOH (2010) separates public health into three domains as per Griffiths et al (2005):

- Health improvement – which includes the wider social influences and inequalities as well as improving lifestyles
- Health protection – which includes infectious disease, environmental hazards and emergency preparedness
- Health services – which includes planning, efficiency, audit and evaluation

The British Medical Association (BMA) (2012) argues that the health improvement domain of lifestyle-related disease now dominates the agenda. They state that poor diet, lack of physical activity, smoking and alcohol consumption are currently the biggest lifestyle risks for morbidity and mortality. Although this research study is not tackling the inequalities and social influences on a wider scale, it is placed within that domain as a possible approach to improving individual lifestyles. The next section looks specifically at the health promotion aspect of public health to assess where the study would fit in current policy.

### 5.2.2 Health Promotion Definitions

The starting point for health promotion has been seen as the Ottawa Charter (WHO, 1986). The five key themes of the Charter are:

- Building healthy public policy
- Creating supportive environments
- Developing personal skills through education and information on health and life skills
- Strengthening community action
- Orienting health services towards prevention and health promotion

Clearly the charter covers the themes of public health as well as health promotion but it is seen as particularly important in the development of health promotion due to its encompassing of the wider determinants of health (Needle et al, 2011).

Within the Charter, WHO (1986) defined health promotion as *“the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.”*

It is clear from this definition that health promotion is a two-fold process of improving the health status of individual and communities and also about empowering people to have more control over their health (Scriven, 2010). What is particularly significant is the focus on responsibility of the individual to take control and to improve their health.

Health promotion has itself been separated into three levels of activity: primary, secondary and tertiary (Scriven and Atwal, 2004). Primary includes health education and legislation aimed at the well population to prevent ill health. Secondary activity includes approaches to change health-damaging habits to prevent development of ill health towards a chronic stage. Tertiary activity concerns people with existing long term conditions or disability to enable healthy living (Scriven and Atwal, 2004).

It would appear that the expression 'long term' condition has been used synonymously with 'chronic' conditions. The WHO (2002) defines chronic conditions as those which require ongoing management over a period of years, and includes such conditions as heart disease, diabetes and asthma. Nolte and McKee (2008) suggest that, in addition, chronic conditions involve input from a range of healthcare professionals to minimise distressing symptoms, prolong life and enable the individual to enhance quality of life. Nolte and McKee (2008, p.4) give a summary of the realities of living with a chronic condition in which people have *"to alter their behaviour and engage in activities that promote physical and psychological well-being, to interact with healthcare providers and adhere to*

*treatment regimens, to monitor their health status and make associated care decisions, and to manage the impact of the illness on physical, psychological and social functioning*". Not only is there much to manage but long term or chronic conditions can create a range of issues that change over time, can be unpredictable and thus form challenges for both the individual and the healthcare providers (The Health Foundation, 2013).

The statute (Great Britain. Health and Social Care Act 2012) devolved responsibility from central government to regional councils to take public health and health promotion closer to population needs. However as Lucking (2006) argued, prior to this devolution, a change of location is not necessarily the solution, and changes in the way healthcare is delivered are required for a more flexible service to meet needs. This is possibly one argument for the different approach that occupational therapy could offer. The next section discusses the way in which healthcare is modelled currently to meet those needs.

## **5.3 Healthcare Delivery Models**

### **5.3.1 Models to Support Self Care**

A number of models of health and social care have been proposed to support health promotion. Figure 9, based within the secondary level of activity for health promotion, shows the structure proposed for supporting people with long term conditions. The aim of this model, based on the Chronic Care Model (Wagner et al, 1999), is to enable health and social care organisations to take a systematic approach to improving care.

The NHS and Social Care Long Term Conditions Model

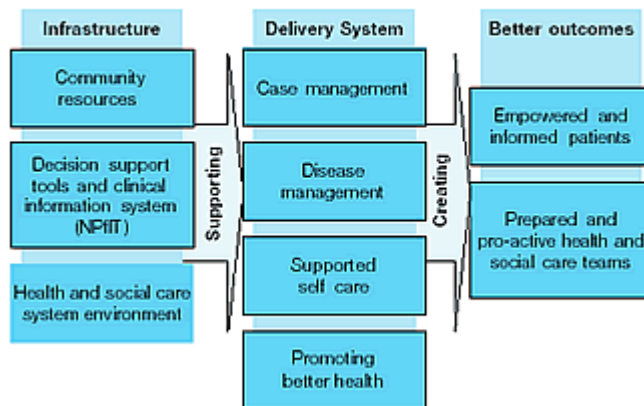
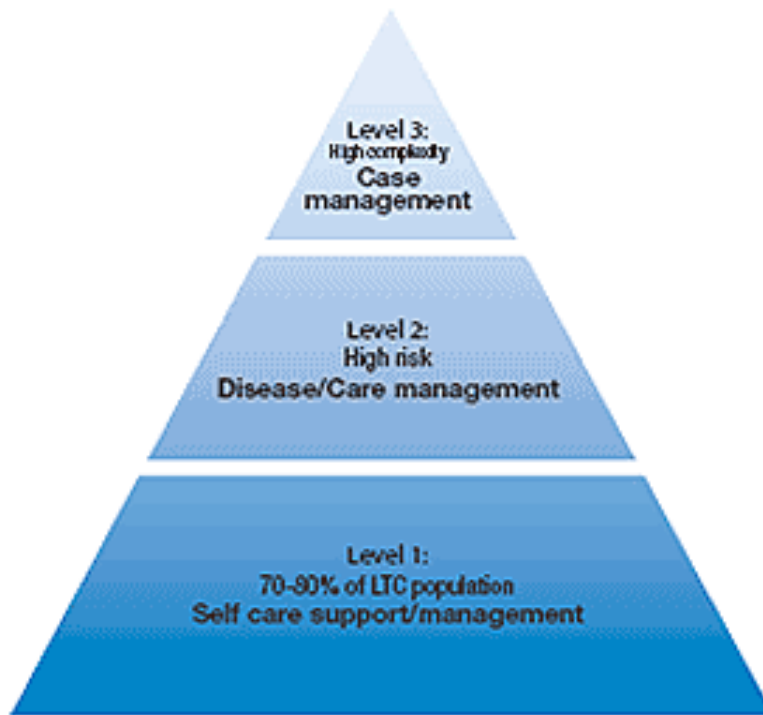


Figure 9 The NHS and Social Care Long Term Conditions Model (DOH, 2005a, p.9)

The Chronic Care Model acknowledges the complex and multi-dimensional needs of supporting and improving health, which includes the wider infrastructure of the healthcare organisations, the specific delivery of care, and the health outcomes (Singh and Ham, 2006). Figure 9 shows the wider infrastructure which supports the delivery of care, which aims to create the outcomes of a well informed population able to take responsibility for their health needs, supported by proactive health and social care teams. However because of the interacting systems it has been difficult to establish which particular aspects of the model improve either the quality of healthcare or the clinical outcomes (Singh and Ham, 2006).

In an attempt to give more detail of the delivery system of the Long Term Conditions Model, The NHS and Social Care Model also incorporates the Kaiser Permanente Model (see Figure 10), a pyramid of care identifying the needs of

people with long term conditions into three groups. One of the pillars of this model is supported self care.



**Figure 10 Kaiser Permanente Model (DOH, 2005a, p.10)**

The bottom of the pyramid in Figure 10 addresses the needs of the majority of the population with long term conditions. Level 1, to a large extent, lays the responsibility for health at the individual level but it is also the responsibility of the healthcare professionals to ensure that those with long terms conditions have the skills and knowledge to best understand and deal with their condition (DOH, 2005a). As previously discussed in chapter 3.4.2 (p.26), people with diabetes are estimated to have only 3 hours of contact per year with healthcare professionals (DOH, 2005d) and are expected to take on all aspects of self care, which suggests that ‘supported’ self care (as in Figure 9) is limited. Not only does self care include understanding and complying with medical regimes and self

monitoring but, more broadly self care also includes the actions people take to *“stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital”* (DOH, 2005b, p.1).

### **5.3.2 Self Care or Self Management?**

Before looking further at this model of self care and whether it is working as a structure to help people manage long term conditions in general, and diabetes in particular, it is important to discuss what actually is meant by the terms self care and self management. Different professions have different views on the topic (as will be shown in section 5.3.3 Self Care and Occupational Therapy, p.73) and, for the purposes of the study, it is helpful to clarify these views.

Self care and self management are sometimes used synonymously in much the same way that it appears that long term and chronic conditions are. Social scientists Coulter and Ellins (2009), suggest that self management is the support and encouragement of self care and that this includes education, training, medical management and emotional support. Lorig and Holman (2003), from the Stanford University School of Medicine, advance a similar view and summarise the five core self-management skills as problem-solving, decision making, utilising resources, taking action and partnership formation with healthcare professionals. This view incorporates both the individual and the healthcare organisations. By contrast, psychologists Barlow et al (2002, p.178) define self management as *“the individual’s ability to manage the symptoms, treatment, physical and*



*psychosocial consequences and lifestyle changes inherent in living with a chronic condition*". The Health Foundation (2014a) has yet another view on the subject seeing self care very much as the broad DOH definition above and self management as managing an illness or condition with or without healthcare support.

In many ways it can be difficult to differentiate between the two perspectives but for the purposes of this study, self care will be viewed as the wider health and wellbeing strategies used by individuals to maintain or optimise their health and wellbeing (DOH, 2005b) while self management refers to the specific tasks, skills and strategies undertaken by the individual with a long term condition, as viewed by Barlow et al (2002). Self management includes a complex set of activities. Within diabetes this can include changes to diet, exercise, self-medication, monitoring and testing and attending appointments (Harvey and Lawson, 2009) but is influenced by individual capability and disposition, roles and relationships and the wider economic and cultural environment (Hinder and Greenhalgh, 2012). Thus self management can be socially, physically, intellectually and emotionally demanding (Hinder and Greenhalgh, 2012).

### **5.3.3 Self Care and Occupational Therapy**

One further potentially confusing aspect to this debate is occupational therapy's use of the term self care. Self care was introduced in Chapter 4 (see p.39) as one of three occupational performance areas, the others being work and leisure (Canadian Association of Occupational Therapists, 1997; Creek, 2010). Within the

occupational therapy lexicon self care traditionally includes such activities as grooming, physical fitness and household management (Creek, 2010); washing and dressing (Guidetti et al, 2007); dressing, grooming, walking and eating (Reed and Sanderson, 1999) or, more broadly, occupations for looking after the self (Canadian Association of Occupational Therapists, 1997).

Self care is one of the most frequently used interventions by occupational therapists (Guidetti and Tham, 2002). However it can be seen that the activities included appear to be much more limited than the DOH (2005b) definition above or indeed that of self management. Van Huet et al (2010, p.342) open out the definition of self care to the tasks necessary to ensure “*health and wellbeing and survival in society*”. While this seems to include more of the vision of self care as described by the DOH (2005b), they suggest that this incorporates eating, toileting, personal hygiene, dressing, shopping, communicating, money management, travel and mobility, meal preparation, sleeping and sexual expression (Van Huet et al, 2010).

It is interesting, however, that no mention is made of medication, testing, engaging in healthcare appointments and medical regimes, nor the broader self care actions in terms of health promoting strategies mentioned in the previous section. Although, as Van Huet et al (2010) comment, engaging in self care is recognised as a core part of occupational therapy practice, it would appear that occupational therapy is perhaps narrowing its definition of self care at the expense of these broader self care actions. This is somewhat puzzling given that

occupational therapists recognise that an individual's beliefs and values and the environment in which self care takes place are important in terms of influencing how well a person engages in self care (Van Huet et al, 2010). This implies that the actual doing of self care is very complex. Van Huet et al (2010) argue that occupational therapists consider self care mundane and routine, although this could be because they are working to a restricted definition of self care.

A return will be made to this topic in Chapter 13 Theoretical Discussion, p.291. It is possible that the area of self care from an occupational therapy perspective may need to be widened to incorporate the self care language of health delivery models in order to position the profession in the current health service context.

#### **5.4 Self Management and Self Care Models – Do they Work?**

Despite healthcare policy based on self care and self management models, the evidence suggests that not everyone is likely to engage in the recommended behaviours. Dunbar-Jacob et al (2009) state that non-adherence rates to healthy behaviour change in practice and research range from 20% to 80%. They argue that this may be due to a number of factors such as a complex regime of medication adherence, attitudes towards people on the part of healthcare providers, inadequate information/instruction, and convenience. In addition they suggest that there are certain individual characteristics which impact on adherence such as psychological characteristics, motivational factors, behaviour and health literacy (Dunbar-Jacob et al, 2009).

Williams et al (2009) focus on the psychosocial issues around health promotion and non adherence. They suggest that an individual needs to know what to do, want to do it and be able to do it. Hibbard et al (2004) address the question of how people become motivated or “*activated*” to take charge of their health and developed a measure to assess people’s level of activation in order to tailor intervention to that person’s level. This method, known as “patient activation” is concerned with enabling people to engage with the whole process of managing symptoms and problems, maintaining function, reducing ill health and being an active partner in any decision making (Frosch et al, 2010). The critique of this approach is that it assumes that individuals are rational, able to calculate risk, have an accurate perception of the nature of their condition, and take action accordingly (Morden et al, 2012; Skinner, 2004; Zoffmann and Kirkevold, 2005). Morden et al (2012) argue that risk is not a rational category but varies according to the individual’s illness experience, varying with time and circumstance. In addition self care is seen by the health professionals in terms of successful compliance with a prescribed regime (ie that the healthcare professional is the expert and that compliance is necessary to avoid complications). The presence of ‘untoward symptoms’ is thus seen as non-compliance and a failing on the part of the individual (Paterson et al, 2001; Sadler et al, 2014). Additionally this approach implies a very reductionist and biomedical framework (Pickard and Rogers, 2012) and the very use of the word ‘patient’ suggests dominance on the part of the healthcare professional. Being mindful of this, this study refers to people and individuals rather than patients.

The biomedical framework does not address how people actually cope in terms of everyday life (Sadler et al, 2014). Although the models discussed above imply a shift in responsibility from the healthcare professional to the individual (especially in terms of people with diabetes having only three hours of contact time with health care professionals per year), it has been argued that this is still a paternalistic approach and promotes compliance rather than health (Sadler et al, 2014). The self management behaviours that are promoted, such as exercise or healthy eating, tend to focus on populations and communities rather than the individual (Moll et al, 2013) which cannot take account of individuals' personal worlds (Skinner, 2004). The significance for occupational therapy is the potential to shift the perspective from a bio-medical compliance-led approach to placing self management within a social model, in terms of the individual in their own context.

## **5.5 Allied Health Professionals and Health Promotion**

As part of the government initiatives discussed above, the health agenda expects all Allied Health Professionals (AHPs) to promote health and wellbeing and to view every contact as an opportunity for health promotion (DOH, 2003; DOH, 2005c; DOH, 2008). In their systematic review, Needle et al (2011) found that on the whole health promotion was seen as a routine component of AHP practice but that interventions, in terms of the research evidence, were poorly planned with little systematic delivery and evaluation was weak. Needle et al (2011) suggest that the history of policy in healthcare has largely ignored the potential

contributions of AHPs and that this may be partly due to a lack of understanding of the roles that AHPs play. Law et al (2005) propose that this role is generally seen as alleviating the impact of illness or disability rather than promoting health and wellbeing. The Health Foundation and Nuffield Trust (2014b) also comment that AHPs rarely appear in major policy and that AHP contribution could be overlooked or undervalued.

As one of the Allied Health Professions it would seem that, theoretically, occupational therapy would be well placed to help meet the health promotion needs of people with long term conditions. Scriven and Atwal (2004) suggest that occupational therapists are already involved in the secondary and tertiary aspects of health promotion while the College of Occupational Therapists (2008) recognises and supports occupational therapy's role in promoting health and wellbeing. Many of the profession's core skills and beliefs, such as the impact of lifestyle choices and environmental influences on health and wellbeing, appear to sit within the domain of health promotion (Christiansen and Matuska, 2010; College of Occupational Therapists, 2008). However, in practice, occupational therapy's role in health promotion is not well recognised (Moll et al, 2013). The core skills and beliefs in terms of health promotion are not always recognised among therapists (Aguilar et al, 2013) and the bio-medical setting in which many therapists work can lead to a much narrower focus of practice (Molineux and Baptiste, 2011; Wilding, 2011). In addition, limited understanding of the occupational therapy role by other professionals appears to have restricted the

role of occupational therapy generally in health promotion (Ashby et al, 2015; Wood et al, 2013).

## 5.6 Summary

This chapter has addressed the current context of public health in the UK. It has reviewed models of care for long term conditions, and examined the concepts of self care and self management. The terminology of self care in occupational therapy has been questioned, as well as the theories behind the self care model which appear to focus on compliance rather than health and well-being. Lastly this chapter has reviewed the role of allied health professionals within the healthcare agenda and started to address the differences between theory and the realities of the work setting. As The Health Foundation (2011) suggests, despite the policy and the theories around long term conditions, there is a huge gap between the rhetoric and actual clinical practice. The following excerpt reflects on a quotation found in The Times.

### *Reflection on opinion and public health:*

*There was a quote in yesterday's Times (15/12/14) in The last word which I cut out: "Opinion is ultimately determined by the feelings, and not by the intellect" Herbert Spencer, philosopher, Social Statics (1850)". In terms of intuitive inquiry there are a lot of quotations from The last word which have made me think about the wider aspects of the research. When I initially saw this I was thinking about the row that is on-going about immigration and the many statements that the media have recorded from the general public and politicians and the storm that UKIP is creating which is causing divisions. Many banded about statements around "they" come over here and take all our jobs - which is clearly an emotional response despite the apparent statistics that say our economy would collapse without people coming in to do jobs that "we" apparently won't do and the evidence that collectively the*

*government is getting more in tax than giving out in benefits. But also in terms of health behaviours and in relation to the health models I looked at yesterday, many of the criticisms of the models are that they assume rational behaviour when it is probably the case, as above, that we are all making decisions on the way we feel about it. I wonder whether this is where the education can fail? Is this something to think about for the future?*





**Figure 11 Illuminated thoughts**

*This paper and material weaving includes shapes and lines painted on to cotton with gloss gel medium, gold and silver paint and ink tense pencils. I wove the paper and cotton together, with different widths of material woven horizontally and then at the bottom vertically. This was to show how thoughts change direction. The symbols and bright colours depict different areas of thought and ideas. This is my attempt to represent creativity, interconnections, shedding light, illumination, inter-relationships, and meanings within meanings. These are all the things that I am thinking about in relation to the research and also what the research is changing in my head.*

## **6.0 Metaphor and the Language of Ill Health**

### **6.1 Chapter outline**

Metaphors abound in the language of medicine and ill health, and they are often not recognised, accepted without thought, or seen merely as decorative aspects of language (Childress, 1997; Geary, 2011). Metaphors can have profound professional, social and political implications and if not identified can result in the unwitting spread of those worldviews (Bolton, 2010). For instance a closer examination of the metaphors of medicine reveals many metaphors of warfare against disease and power relationships which then influences and directs intervention (Childress, 1997; Hamilton, 2012; Penson, et al 2004; Radley 1995). By implication this ignores the illness representations and experiences of the person receiving this intervention (Skinner et al, 2011).

An examination of the literature on metaphor became an important consideration in the study, especially in response to cycle 4 of the intuitive inquiry process for Study 1 (see Figure 2, p.6) when extra literature was sought after my own use of metaphor in conceptualising the participants' experience of diabetes, and when contemplating its use as a means of exploring the lived experience of diabetes for the participants. Additionally this part of the literature review gave insight into the descriptions given by participants of their healthcare appointments. This chapter explores definitions of metaphors. It focuses on specific examples of the use of metaphor in healthcare and ill health to show the impact of metaphorical language on institutions, healthcare professionals and

people with illness or long term conditions. It examines the potential of metaphors to create or maintain stigma and stereotypes and finally discusses the value of metaphor in understanding individual illness perspectives.

## **6.2 Definitions of Metaphor**

There are many definitions of metaphor and the most quoted is that from Lakoff and Johnson (1980, p.5) *“the essence of metaphor is understanding and experiencing one kind of thing in terms of another”*. Bolton (2010, p.221) describes metaphor as *“the frame through which we perceive, understand and feel”* and thus make sense of the world. It is not just about comparing one thing with another but highlighting particular features and creating new domains of meaning (Radley, 1995). For example, a common metaphor is that of ‘life as a journey’. By mapping the idea of a ‘journey’ onto ‘life’ this can identify other ideas such as someone having a *“single track mind”* or *“being at a crossroads”* where the person is seen as a traveller with purposes as destinations and choices as junctions (Gauntlett, 2007 p.142). The metaphor can be extended to seeing obstacles as ‘bumps in the road’ and ‘travelling companions’ as facilitators in life’s journey (Zaltman and Zaltman, 2008). Although metaphor can help with understanding it can also restrict understanding. Geary (2011) suggests that metaphor is a paradox because, although it compares one thing with another, it also tells us what it is not. Childress (1997) explains this by exploring the metaphor of argument as warfare. He suggests that this highlights the idea of conflict yet hides other aspects of argument such as cooperation and collaboration.

Metaphors have two main components: the focus or target, and the vehicle or the source domain (Cameron, 2003; Gauntlett, 2007). In the example above of 'life as a journey', the 'journey' is the vehicle for describing the target 'life'. In this way the metaphor is a linguistic convention and also a conceptual one, describing and explaining certain aspects of life in relation to a journey (Lakoff and Johnson, 1980).

### **6.3 Metaphors of Healthcare And Ill Health**

The many metaphors for ill health and healthcare will be discussed below. It is also important to note that 'health' is itself a metaphor for being productive and useful, and that by implication, ill health can be viewed negatively as a breach of the norm (Ferguson, 2010). Radley (1995, p.119) suggests that metaphor can be helpful for both showing the difficulties of living with an illness in the world of health and to make that situation "*viable and comprehensible*". The metaphors used to describe the positive or negative aspects of this experience can thus be value laden (Petersen et al, 2001). A review of the literature indicates that the main metaphors used in health care are military, machine, journey, sports, balance and control, and business metaphors. Examples of these are now explored to explain the impact on the individual and the healthcare professional and how they might overtly or unwittingly influence ideas around self management.

#### **6.3.1 Military metaphors**

The most common metaphor in healthcare is war. In this metaphor illness is an attack on the body (Petersen et al, 2001). The doctor battles against disease, a

battery of tests is ordered, a plan of attack is devised against the invasion of germs, magic bullets come from the arsenal, conditions are treated aggressively and compliance is expected (Childress, 1997; Hamilton, 2012; Penson et al, 2004). This metaphor is pervasive and persuasive and shapes the medical approach to disease management. It can demand the 'fighting spirit' of the person with an expectation that the person will 'fight for their lives' or 'put up a struggle' (Petersen et al, 2001). This can be seen as both positive and negative: the idea of 'opposing' and 'battling' could inspire someone to take positive action yet could equally well create a burden exhausting to deal with, which focuses on the negative effects of the condition (Hamilton, 2012; Radley, 1995). Sontag (1978), for instance, reported that military metaphors contributed to stigmatisation of her cancer, they had a controlling influence and that they made her experience worse. If medicine is seen as a battle then there are issues of judgement that if people lose the battle, they did not try hard enough (Petersen et al, 2001). In its extreme a person can even be viewed as the 'enemy' for surrendering (Childress, 1997). The military metaphor can also result in overtreatment, particularly in terminal illnesses where healthcare professionals and families can be reluctant to let people die. In this metaphor withdrawing treatment can be seen as a surrender and death as defeat (Childress, 1997).

The military metaphor has been applied to diabetes self management. Pray (1983), cited in Childress (1997, p.6) discusses how it made it difficult for him as a teenager to "*conquer*" his diabetes. It was only when he stopped viewing it as the "*enemy*" to be conquered and saw it as a "*teacher*" that he made progress

towards living successfully with his diabetes. Other criticisms of the military metaphors include the repercussions of the view of medicine's war on, and description of, epidemics. Previously focussed on AIDS, and now more increasingly on obesity and type 2 diabetes, the person with the condition is seen as the 'enemy' as much as the condition and this can lead to blame and punishment from both healthcare and society (Childress, 1997). For example, causes of ill health can be seen as giving into dietary temptation or being lax with self-management (Ferguson, 2010). Diabetes is frequently described as a 'burden' on society and even as the "*Black Death of the 21<sup>st</sup> Century*" (Matthews and Matthews, 2011, p.2). This has contributed to the stigma felt by people with diabetes, as described in Chapter 3.5 (p.33).

Military metaphors have also been criticised for reinforcing male dominance in healthcare (Penson et al, 2004) and for ignoring the other influences on a person's experience of ill health (Petersen et al, 2001). As Hasselkus (2011) comments, the military metaphors also mean that the disability or illness is medicalised and that the expectation is that the person is framed and defined by certain rules to 'conquer' this disability. This is reflected in the idea of self care, from a bio-medical perspective, being about compliance (see Chapter 5.4, p.76). Hasselkus (2011) suggests that the opposing holistic view is that illness and disability are natural – and that wellbeing can be achieved by accepting and living within the boundaries of the disability or condition.

### **6.3.2 Machine metaphors**

The predominant model in Western medicine is the biomedical model, in which there is a linear cause and effect between symptoms and disease process (Quintner et al, 2008). The assumptions of this model are that illness (symptom) has an underlying cause (disease or abnormality) and that removal of this disease will result in health (Wade and Halligan, 2004). By its nature it is very reductionist (to the biological level) and other factors associated with illness, such as social, psychological, behavioural or environmental factors, are ignored or relegated (Petersen et al, 2001; Quinter et al, 2008; Rogers, 1982; Wade and Halligan, 2004). The metaphor that arises from this model is that of 'body as machine' with the assumption that it can be mended like a car while documentation logs the faults and repairs as in the car owner's handbook (Bolton, 2010). Critics argue that this metaphor separates the person from the illness where the person becomes the 'innocent' bystander (Sontag, 1978) or becomes 'transparent' as the doctor works on the disease (Hawkins, 1999). In addition the metaphor fails to consider the impact of feelings, choices, social contexts and the whole illness experience of individuals. Mattingly (1994a) suggests that it separates the mind from the body and emphasises the importance of diagnostic tests at the expense of understanding the person's insight into their illness.

### **6.3.3 Journey metaphors**

In terms of a journey, illness has been described as being in a particular place, such as the kingdom of the sick, as described by Sontag (1978), being without a destination or a map (Frank, 1995) or being stuck and immobile (Fullager and

O'Brien, 2012; Mallinson, Kielfhofner and Mattingly, 1996). Zaltman and Zaltman (2008, p.91) discuss participants who stated that before developing diabetes they felt they were in charge of the journey of their lives but after diagnosis felt that diabetes was "*in the driver's seat*". They suggest that this journey metaphor can be used positively in terms of resources for helping the person "*to get back behind the wheel*" in their journey. Others have used journey metaphors to symbolise recovery as a journey to self-knowledge and feeling alive (Fullager and O'Brien, 2012); being on the path to recovery (Penson et al, 2004); or reorientating themselves in a new direction to accommodate the illness or condition into their lives (Radley, 1995).

#### **6.3.4 Sports Metaphors**

Clearly there are overlaps between the military metaphor and sports metaphors, both involving some measure of competition, sides, winners and losers. There are also overlaps between sports and journeys where races, either on land or sea, also take on aspects of journeying from one place to another, goal setting and reaching a destination. Seale (2001) reviewed newspaper articles about cancer to analyse the metaphors used by both journalists and members of the public. He found that many of these involved metaphors of '*racing*' for cures, '*climbing the mountain*' of recovery, and '*winning the bout*', where the metaphor of the '*heroic struggle*' turned people into sporting heroes. Penson et al (2004) discussed the use of the '*game plan*' metaphor with children with cancer as an alternative to the more potentially worrying ideas of the military metaphors.



### 6.3.5 Balance and Control Metaphors

Zaltman and Zaltman (2008) see balance as one of the metaphors that people develop very early on in terms of health and wellbeing. The assumption is that mind and body are normally balanced and that illness is a state of imbalance (Gibbs and Franks, 2002). Disease is seen as *“not at ease”* and the need to achieve a balance, they state, is deeply rooted to achieve *“physical, psychological or social equilibrium”* (Zaltman and Zaltman, 2008, p.47). People seek to achieve control of this state of imbalance, to start to normalise the experience (Radley, 1995) and describe metaphors of entrapment and lack of choice (Mallinson et al, 1996) to express this lack of control. People with diabetes describe the condition as having metaphorically *“hijacked”* their lives (Zaltman and Zaltman, 2008, p.174) or as diabetes *“giving orders and wreaking havoc like a bull in a china shop – and I am the china shop”* (Zaltman and Zaltman, 2008 p.175). Another metaphor for control compares a participant’s relationship with diabetes to that of dog and master *“if you can discipline it, keeping it balanced in order to let it follow you, if you can lead and control scrupulously without being scared, without letting it control you, then you feel better. Those who manage this have mastered the disease.”* (Ingadottir and Halldorsdottir, 2008, p.610).

### 6.3.6 Business Metaphors

Business metaphors are used more by healthcare institutions than by people in relation to healthcare. McIntyre (1985) argues that managers are concerned with efficiency and thus view people as financial assets or costs rather than moral or feeling human beings. Bolton (2010) suggests that within the health service this business metaphor can lead to healthcare professionals viewing their clients

as problems rather than “*unique people with unique needs*” (Bolton, 2010, p.37). Certainly the rhetoric of people as ‘bed blockers’ (Mur-Veerman and Govers, 2011) appears to back this up and can reduce people to economic units and imply that they are to blame. Similarly referring to people as a bed number (Baier and Schomaker, 1995) dehumanises people in hospital at the cost of care and compassion. Childress (1997) argues that the military metaphor also impacts on the allocation of resources in healthcare whereby priority is given to critical care interventions and ‘killer’ diseases such as cancer, rather than to long term or chronic conditions such as diabetes. In addition priority can be given to technological intervention rather than non technological caring and rehabilitation.

#### **6.4 Mixed Metaphors and Mixed Messages**

Petersen et al (2001) argue that it is crucial to understand the differences between the healthcare professional’s metaphor, the person’s metaphor and the institution’s metaphor. They contend that the closer the match the more likely progress will be made. As Zaltman and Zaltman (2008) note, different metaphors between healthcare professionals and individuals can result in mixed messages. In their research they found that healthcare professionals saw themselves as a resource for managing or curing disease (business and military metaphors). By contrast people viewed the professionals as reminders that their bodies were flawed containers. This latter metaphor meant that they saw little value in medical resources because the idea of taking medication renewed their view of

being flawed. This impact of language could well have consequences in terms of self management.

Understanding someone's experience of their condition would appear to be one of the most important communication skills that healthcare professionals can offer. Steslow (2010) gives a very powerful and highly articulate account of her own experience on a mental health ward where she found that only by using the medical terminology used and understood by the staff could she convince them that she was compliant and making progress. However psychiatric diagnosis and medical terminology gave only a very partial insight into her condition and did not enable her to explain or allow others to understand her experience. She argues that the person's "*idiosyncratic metaphors*" need to be shared so that medicine does not confine itself to a biochemical response and thus silence a person's own metaphors (Steslow, 2010, p.31).

The language used by professionals or the media can be pervasive and striking. Cancer has been described as a metaphor for "*all things corrupt and unclean*" (Czechmeister, 1994, p.1229) with connotations of the fear and superstition around the plague. As mentioned previously, Matthews and Matthews (2011) liken diabetes to the bubonic plague, suggesting that the poor cheap food and sedentary lifestyle of our current society have turned diabetes into an infectious disease. These metaphors, while very powerful, could potentially have a negative impact on those who develop the condition, as described in Chapter 3.5 (p.33).

Childress (1997) argues that within healthcare the military metaphor is more accepted than that of a journey because it fits the culture of a doctor as a 'general', rather than as a 'guide' on the person's journey. Given that the models of healthcare described in Chapter 5.3 (p.69) are now those of empowerment and self-management it will be interesting to note if and how those metaphors change with new models or whether the pervasive institutional metaphors prevent this paradigm shift. It is argued that exploring people's metaphors can contribute to this shift of emphasis by helping healthcare professionals to see beyond treatment, compliance and self management (Fullager and O'Brien, 2012).

## **6.5 The Value of Metaphors**

It can be seen that metaphors have the potential to create stigma and impact negatively on health behaviours. However metaphors also have value in allowing a certain level of safety by conveying meaning without being explicit (Bolton, 2010). Analysis of metaphor allows us to tune into somebody else's ideas, thoughts and feelings into how they make sense of the world (Cameron, 2003; Cameron and Maslen, 2010; Mallinson et al, 1996) and helps understanding of the lived experience (Czechmeister, 1994). In addition metaphors enable a reshaping of the way we look at things and can structure our experiences (Gauntlett, 2007; Geary, 2011). Lakoff and Johnson (1980 p.145) also suggest that *"new metaphors have the power to create a new reality"* especially where exploration of that metaphor guides future action. As Geary (2011 p.207)

explains, “a good metaphor, like a bolt of lightning, provides a sudden flash of insight”.

## 6.6 Summary

In summary metaphor is valuable as a (metaphorical) bridge between treatment and the experience of illness (Penson et al, 2004). The metaphors people use name and frame the issues that they are experiencing in ill health and can structure possible solutions (Mallinson et al, 1996). It is also clear that metaphors used by healthcare staff, deliberately or unwittingly, can influence a person’s beliefs and attitudes towards that condition (Geary, 2011). Zaltman and Zaltman (2008) and Steslow (2011) argue that it is important for healthcare professionals to validate a person’s metaphor for use in therapy or, as Mallinson, et al (1996) suggest, to reframe possible solutions using a different metaphor. It is possible that the use of metaphor may not apply to everyone, although Lakoff and Johnson (1980) suggest that conceptual thinking is metaphorical in nature and that the use of metaphor is pervasive. The following excerpt reflects on a newspaper column about the use of metaphor.

### *Reflections on the use of metaphor:*

*Interesting article by Melanie Reid in her Spinal column in the Times magazine today (15/11/14). She was talking about the recent debate about using military language to describe disease - and how most of us use the war metaphors for ill health without thought. She reflects on how she used the language of a “romantic warrior” at times to get through the worst of her times but also how she might have unconsciously set herself up for a fall - using the language of battling and fighting her spinal injury means that having not ‘conquered’ it, she could consider this somewhat of a failure of not having tried hard enough, and made it equally difficult for friends and*

family. She also talked about Semino's project with the NHS, creating a metaphor manual to help people to use imagery or metaphor to express difficult emotions. Melanie Reid comments that she fears the end result may "lead to more clumsy NHS word policing" and potentially ignore the fact that everyone needs to use their own words as their condition is, after all, uniquely theirs. Every time I go back to the transcripts I find more examples of metaphor. I will need to go back to the others to see if/ how much I've missed. It takes me back to the earlier conversations with Betty [Hasselkus] about the artwork (Gifford: 'the human mind is not, as philosophers would have you think, a debating hall, but a picture gallery) and how at that time I had missed the fact that my art was also expressing metaphor. (November 2014)



**Figure 12 Immersion**

*This "Immersion" collage was made by cutting up a previous acrylic painting into waves and curls. I added a photograph of me swimming (bottom left hand corner) to complete the collage. For me this represents being immersed in the data. I'm down there and not in the middle because this is a tentative immersion. The waves demonstrate the twists and turns, the dead ends and the feelings I have of being weighed down by the data and the uncertainty of how to get it right. It is also about not making assumptions about my approach and ensuring that I explore the possible ways that analysis might take me and ensuring that I remain immersed.*

## **7.0 Literature Review Summary and Research Question**

The previous chapters have reviewed the literature on diabetes and current approaches to enable people to manage this condition. Occupational therapy's particular occupational perspective on health has been discussed and initial consideration given to how its approach might fit into the current healthcare agenda of self management of long term conditions such as diabetes. Some issues have been identified as to differences between occupational therapy theory and practice. The healthcare agenda has been discussed through an exploration of the theory and practice of public health, health promotion and models of care. This has included analysis of the biomedical approach to self care and the potential difficulties of translating this into daily lives. In addition the language and metaphor of medicine and ill health has been considered in relation to those models of care, individual experiences of diabetes and interactions with healthcare professionals.

The overview of the literature suggests gaps in understanding of diabetes from the lifestyle perspective, both in self management and in prevention. Although the lived experience has been addressed, the focus has been on compliance through achieving and gaining control of diabetes, rather than on the day to day living with diabetes, and how this impacts on and is impacted by daily occupations. In addition it appears that there is paucity of evidence to show how self management strategies shape occupational participation.



Metaphor appears to have a role in helping with understanding this lived experience, but the literature reviewed did not focus on how the metaphors that people with diabetes used, could specifically help with communicating that experience or influence the therapeutic relationship.

Within the occupational therapy literature reviewed it appears that the role of occupational therapy is not clearly defined to enable the incorporation of diabetes self management into daily routines. Indeed the whole concept of self care, may have been too narrowed by the profession so that it excludes the wider social, physical and psychological perspectives of the health and wellbeing of the individual. The language of occupational therapy, it has been suggested, may be influencing the scope of practice and may limit its focus on positive participation in occupation for health and wellbeing.

These gaps in understanding form the basis of this study's exploration of the role of occupational therapy in diabetes self management.

## **7.1 Focus of Current Study and Research Question**

The focus of this study is the role of occupational therapy in self management of diabetes, based on the life context rather than the medical aspects of this condition. The aim is to:

- explore the lived experience to understand how occupation impacts on and is impacted by diabetes

- explore the use of metaphor as a possible therapeutic medium to improve understanding of people's experience of diabetes
- explore the concepts and language of occupational therapy and how these limit or enhance the potential role of occupational therapy in diabetes self management

***In summary the research question is:***

What can be learned about the occupational experience of people with diabetes and how can occupational therapy enable health and wellbeing through occupation based diabetes self-management?

The next chapter discusses the Methodology, while the following reflection muses on the links between reading, writing and mixed media.

***Reflections on writing:***

*I am reading through and making notes on the dozens of journal articles that I have collected over the previous months in order to start writing. As I get towards the end of the reading and realise that I now have to create the writing, there is a moment of trepidation but also of excitement. It feels like, in mixed media art terms, my STASH. My notes and comments are like the scraps of material or paper or media that the mixed media artist delves into to create the art work. The stash is often kept for years and rediscovered, the artist (in its loosest sense) looks at the stash anew to find things and possibilities that didn't exist in their mind before. Things change so that now a particular colour might resonate leading to a particular creation. In the same way from notes and words, particular phrases spring out and take on new meaning and lead to new creations. In my notes some thoughts are highlighted and some are in different colours - making them the highly patterned bits of paper or material. I have 5 articles still to read that I have marked as significant. They may not be or they may be the linchpin, image,*

*colour that gets me started, around which the other ideas (patterns, colours) fit to form the whole. I have in my mind's eye the process of printing out the notes (which are pretty haphazard) and cutting them out and sorting them into the colours and shapes to form my creation. In some ways I guess this is where the quilting metaphor might for once be apt. The article follows a structure (intro, body, conclusion) with specific headings and it is bound within this - rather than a work of free thinking. The article has rules and form like a quilt and I will be sorting the ideas like patches of material which fit together and make sense together (August 2013).*



## **8.0 Methodology**

### **8.1 Chapter Outline**

This study explores the experiences of people with diabetes in order to inform the development of the role of occupational therapy in self-management. The aim is to honour both the needs of the participants and the core values of occupational therapy. It is important to ensure that the methodology reflects these principles. This chapter will first examine my own ontological and epistemological stance. It will then look at the links between occupational therapy and qualitative research in terms of values and meaning with a more detailed critical exploration to explain in-depth the choices decided upon. Further it will investigate the different approaches within qualitative methodology to ascertain which will most appropriately fit the research question. In addition the concept of bricolage will be discussed, as a qualitative approach and in its relation to both creativity and reflexivity. The concept of qualitative research as a reflexive process will also be discussed with reference to bracketing and finally a framework is proposed to draw all these threads together.

### **8.2 My own Ontological and Epistemological Stance**

It is clear that any research is likely to have a particular construction and viewpoint which does not account for all other realities (Hammell, 2002). In my own study, as a white middle class female occupational therapist, my ideas, understanding and construction are derived from my own social and cultural

background and professional training. Here it would be appropriate to declare my own ontological and epistemological stance.

I hold a naturalist ontological perspective (Filmer et al, 2004) in that what I hold to be true is that there are multiple realities, not just one way of believing or doing. I believe as an occupational therapist that engaging in occupation leads to health and wellbeing (Wilcock, 2006). I recognise that I have also been influenced in my career by the medical model ontology of mind/body split (Bowling, 2009), and cause and effect (Miller and Crabtree, 2005), as reflected in other chapters. In relation to diabetes this model suggests that the medical view of and approach to diabetes is very much around a successful metabolic control (NCCC, 2008). However I believe that each person with diabetes will have their own experience within their own particular context and thus I need to be clear about my own values, beliefs and assumptions and to reflect on these in relation to the study to ensure that participants are represented fairly (Kristensen et al, 2012).

On this basis my epistemological stance is that of a critical constructivist (Kincheloe, 2005) which, in my view, accepts that the views of the participants will reflect the current social and cultural impact of living in the UK (and for one participant in the USA) in the 21<sup>st</sup> century. In addition this approach recognises that their views are valid and need to be taken into consideration when looking at how best to enable people to self-manage their diabetes.

This means that it is important for me to use different perspectives to understand their reality but also to honour the core values of occupational therapy. The next section explores those perspectives to see which would best enable this understanding.

### **8.3 Occupational Therapy and Qualitative Research**

Occupational therapy has a set of core values which it shares with other health professions. These are the values of altruism, dignity, equality, freedom, justice, truth, and prudence (Kanny, 1993). Peloquin (2007) suggests that another five should be added to this list, those of courage, imagination, resilience, integrity and mindfulness, to reflect occupational therapy's humanistic philosophy and the practical realities of working in the profession. These values could equally apply to the qualitative researcher (Dadds and Hart, 2001; Finlay, 2011; Hammell, 2001; Tracy, 2010; Whiteley, 2012).

In terms of core beliefs, the central argument within occupational therapy is that engaging in occupation leads to health and wellbeing (Wilcock, 2006). To incorporate this belief into intervention, occupational therapists use the core skills of collaboration with client; assessment; enablement; problem solving; using activity as therapeutic tool; group work; and environmental adaptation (College of Occupational Therapists, 2013; Creek, 2003). The problem solving within occupational therapy is approached through a process of clinical reasoning. Here researchers see many parallels between occupational therapy and qualitative research. Mattingly (1991a and 1991b) describes one kind of

narrative reasoning as a deeply phenomenological process of understanding an individual's meaning of their illness experience. Finlay (1999, p.300) similarly describes how phenomenology matches the therapeutic style of the occupational therapist, being the link between the research methodology and the "*humanistic values*" of the therapist.

In addition the attempt within qualitative research to understand the participant in a non-judgemental way and with respect (Charmaz, 2006) is mirrored within occupational therapy's Code of Ethics (COT, 2015). Hammell (2001) cautions that in order to undertake qualitative research that is truly client centred, researchers must adhere to the Code of Ethics and Professional Conduct (College of Occupational Therapists, 2015) to ensure that power is realigned to collaborate with participants as far as possible. This is explored further in Chapter 9, Study Design.

Hammell (2001) summarises the many parallels between qualitative research and occupational therapy as follows:

- Both seek to understand the perspective and values of the participant/client
- Both view the individual as inseparable from their context or environment
- Both have methods and tools to explore the individual's belief and value systems

It would appear that these epistemological and ontological parallels between qualitative research and occupational therapy ensure compatibility.



Allsop (2013) has argued that quantitative methodology has been the dominant approach in health research and generally quantitative research methods have been placed higher in the hierarchy of health research methodology, with the randomised control trial seen as the gold standard (Muncey, 2009). However health care has been recognised as complex (Sweeney, 2002) and qualitative methodology allows for observing and interpreting this complex reality with the aim of *“an elaborate description of ‘meaning’ of phenomena for the people or culture under examination”* (Newman and Benz, 1998, p.9). The following section considers definitions and the value of qualitative research as a means of answering the research question.

## **8.4 Definitions of Qualitative Research**

Denzin and Lincoln (2013, p.6) define qualitative research as *“a situated activity that locates the observer in the world.”* They suggest that researchers use a *“wide-range of interconnected interpretative practices, hoping always to get a better understanding of the subject matter at hand”* because each of these practices interprets the world in a different way (Denzin and Lincoln, 2013 p.7). This means that in studying the perspectives of participants in research there can be multiple interpretations (Denzin and Lincoln, 2005).

Qualitative research stems from the human sciences and includes observation, field studies, interviews, document studies, and focus groups (Finlay, 2011; Newman and Benz, 1998) where the emphasis is on understanding meanings and

interpretations. The aim of qualitative methodology is to be inductive and exploratory (Finlay, 2011). The assumptions behind qualitative research are that there is a direct encounter with the world and that, while facts and events are significant, it is how people interpret and give meaning to their experiences which are equally important (Gerson and Horowitz, 2002). This appears to be important for Study 1 in exploring the lived experience of diabetes.

#### **8.4.1 Challenges to qualitative research**

Qualitative research methodology is not without its critics. It is recognised that the researcher's role has an impact on the methodology and that the relationship between the researcher, participants and the context of the research needs to be explored and reflected on (Charmaz, 2006; Finlay, 2011; Green and Thorogood, 2009; Smith et al, 2009). The researcher employs inductive reasoning based on their knowledge, ideas and interactions and hence analysis is not neutral (Charmaz, 2006; Klinger, 2005). In this approach the researcher can have a subjective, emotional or political stance and the aim of the researcher is to understand the participants' world view (Green and Thorogood, 2009). It has been argued that this subjectivity can facilitate discovery (Beer 1997) but there has been criticism that it can potentially result in flawed knowledge (Caelli et al, 2003).

Attempts on the part of the researcher to bracket out their personal values have been challenged (Caelli et al, 2003). Bracketing is seen as a way for the

researcher to set aside their pre-existing beliefs and values (Starks and Trinidad, 2007). However there is little agreement on when and how this happens (Tufford and Newman, 2010). Bevan (2014) suggests that it is not possible to completely set oneself aside but that it is a process of the researcher being aware of the beliefs and values that might otherwise be taken for granted. Overall it therefore requires the qualitative researcher to address these issues of quality through transparency and reflexivity (Hammersley, 2008; Pyett, 2003). This issue is taken up again in Section 8.7 (p.126) and in Chapter 9, Study Design, where I have examined my own views on bracketing and the use of reflexivity in order to promote transparency in the study.

There is much debate about how meanings can be established within qualitative research (Finlay, 2011). For example, the use of interviews has been challenged as a method of obtaining the participant's world view with issues around power, truth and authenticity (Nunkoosing, 2005; Hammersley, 2008). This is further discussed in the Study Design Chapter 9.4 (p.139).

The value of qualitative research is assessed in terms of standards of credibility and trustworthiness, transferability, dependability and confirmability (Guba and Lincoln, 2005). Again there is debate about the ways in which qualitative research can be assessed against these quality markers (Finlay, 2006; Hammell, 2002; Krefting, 1991; Whittemore et al, 2001; Yardley, 2000) and it is clear that this is an important consideration in this research project. Issues of potential observer bias, lack of generalisability, possible lack of focus and poor replication

(Allsop, 2013) must all be addressed and this is further discussed in the Study Design Chapter 9.9 (p. 174).

However, as the research question is centred around understanding the experiences of people living with diabetes and the potential role of occupational therapy in prevention and self-management, it appears that the characteristics and strength of the qualitative methodology make this the approach to take. It is necessary to acknowledge the potential weaknesses but it will allow for a deeper exploration of participants' world view in their natural environment and enables further investigation of the how, what and why of living with this long term condition.

Qualitative research is more than a collection of methods (Creswell, 2013). It has a number of different paradigms and traditions which have changed over time with much debate about meanings and claims to knowledge (Hammell, 2002) and which need further exploration to determine which would be most fitting for this research. This includes an examination of how it is possible to understand the viewpoint of others, how knowledge is developed as well as what particular methods might be best suited to answer the research question. The following section looks briefly at these different traditions in an attempt to pinpoint where this study might fit within the different epistemological stances.

#### **8.4.2 Traditions in qualitative research**

Denzin and Lincoln (2013, pp.5-6) suggest that qualitative research is now in its eighth phase, which they describe as being concerned with the moral discourse of democracy, race, gender, class, nation-states, globalisation, freedom and community. The other phases are assigned to chronological periods as follows: the traditional or positivist phase 1900-1950; the modernist phase 1950-1970 and blurred phase 1970-1986 which they feel was dominated by hermeneutics, semiotics, phenomenology, cultural studies, feminism and the concept of the bricoleur; the crisis of representation 1986-1990; the postmodern (experimental) 1990-1995; postexperimental 1995-2000; and the methodologically contested present 2000-2010. Denzin and Lincoln (2013, p.6) suggest that any definition of qualitative research *“must work within this complex historical field”* because it means different things in each of these different stages.

The positivist phase was concerned with gaining knowledge from what could be observed and measured, and assumed one reality (Green and Thorogood, 2009). The modernist phases resulted from a rejection of positivism and, instead, an acceptance of the philosophy of critical realism – that there is a reality independent of our thinking about it in which observation is fallible and all theory is revisable. Within this phase the epistemological perspective is that each of us is biased by our cultural experiences and world views (Denzin and Lincoln, 2013). This is further described in the constructivist paradigm which holds that our view of the world is based on our perceptions of it and thus reality is seen as socially constructed, derived from both social and historical processes (Green and

Thorogood, 2009). In this view the research perspective becomes how phenomena are constructed and it questions common-sense assumptions that categories are 'natural' rather than social ones. Green and Thorogood (2009) argue that this approach has not been without its critics. They suggest that the use of social categories implies that the researcher sees the issue also through a social construction and thus it would be impossible to stand outside the construction under analysis. The criticism then is around how valid is the knowledge derived from this analysis.

One way to achieve validity is to locate the research phenomena with the specific social or historical context in which it occurs. This is known as the critical tradition and occurs in the blurred phase of Denzin and Lincoln's (2013) chronology of qualitative research. Critical theory assumes that there cannot be pure knowledge and it needs to be unpacked from the processes by which it came to be accepted (Green and Thorogood, 2009). This leads then to the question of which qualitative perspective, within these traditions, should be implemented to best answer the research question.

## **8.5 Perspectives in Qualitative Research**

There are many different perspectives in qualitative research and just as many ways of categorising them (Creswell, 2013). Marshall and Rossman (2011, p.18) helpfully summarise these into three main categories:

- Society and culture, which includes ethnographical approaches, action research, case studies and grounded theory
- Language and communication, focussing on the sociolinguistic approaches of narrative, discourse and conversation analysis
- Individual lived experience, represented by phenomenological approaches, feminist inquiry and life histories

The research question of this study considers aspects of all of these main categories and thus a summary of each of these perspectives follows to identify which approaches will best enable the exploration of the role of occupational therapy in the prevention and management of diabetes.

### **8.5.1 Society and Culture: Ethnography, Grounded Theory**

Marshall and Rossman (2011) suggest that ethnography, action research, case studies and grounded theory all come under the heading of Society and Culture. While there is not space to discuss all aspects of these approaches it is important to consider which might fit the research question and why others were not chosen.

Occupational therapy has its own particular professional culture, so an investigation of its potential role, might lead to consideration of an ethnographic approach. Ethnography, according to Have (2004, p.6), is *“the close observation of the actual, ‘natural’ situations in which people live their lives, trying to*

*minimise the impact of their [researchers'] presence on their subjects' actions".*

Ethnography includes a variety of data gathering such as participant observation, interaction, questionnaires, documents and photographs (Charmaz, 2006; Have, 2004). The goal is to get an insider view – although the outcome, ironically as Charmaz (2006) states, may be an outsider's report. It is clear from the literature that there are few occupational therapists working in the area of diabetes self management currently (Fritz, 2014; Pyatak, 2011a; Thompson, 2014) and thus ethnography does not appear to necessarily be the most appropriate approach to investigating the role of occupational therapy in this study.

Action research has an ideology based on collaboration (McIntosh, 2010). It is concerned with the lived experience of people and integrates research with action and aspires to social transformation and greater social justice (McIntosh, 2010). There are a number of approaches, such as community based participatory research in which a partnership is formed to reduce the distinction between the researcher and the researched (Minkler and Wallerstein, 2010). This approach addresses issues of trust, power and collaborative inquiry with a view to improving a particular issue, such as community health, by reducing inequalities and leading to policy change (Minkler and Wallerstein, 2010). This did not appear to be appropriate for the research question which, at this stage, is still exploratory.

Case studies are used to explore a specific case, for example an organisation or a process within a real-life setting, bounded by time and place, and which is



studied over time (Creswell, 2013). Again, due to the exploratory nature of the research question and the lack of occupational therapists working in this field, this did not appear to be the most applicable approach.

This leaves the question of grounded theory. Holloway and Todres (2005, p.97) describe grounded theory as *“developing plausible and useful theories that are closely informed by actual events and interactions of people and their communications with each other”*. They state the researcher focuses on social and psychological processes such as ‘learning to live with pain’ and in this way grounded theory could also be categorised under Individual Lived Experience. The main difference between phenomenology and grounded theory to explore this lived experience is that the latter seeks to construct a theory that is grounded in the data (Charmaz, 2006) while the former seeks to understand without categorising or developing a theory (Finlay, 2011). Within grounded theory there is a simultaneous collection and analysis of data with a constant comparative analysis to identify similarities and differences (Bluff, 2005). In this way theory is provisional and may change depending on further data, but the outcome is a theory to explain the meaning of the participants’ experience (Holloway and Todres, 2005). Grounded theory is seen as being useful in areas where there is a paucity of theories to explain a particular experience or how people make sense of their situation (Stanley and Cheek, 2003). It focuses on a process or action with steps over time where the researcher attempts to explain this action and the end result is a theory about the topic under investigation which includes causal conditions, strategies and consequences (Creswell, 2013).

This could have been a potential way forward for this study. However the decision was made to concentrate on exploratory approaches both to the lived experience of diabetes and to the potential role of occupational therapy in diabetes self-management.

### **8.5.2 Language and Communication**

A focus on the sociolinguistic aspects of the participants' perspectives is useful particularly in Studies Two and Three (see Chapters 11 and 12). These stages seek particularly to explore the use of metaphor as a way of understanding people's experience of diabetes and to make a closer examination of the professional language of occupational therapy in order to help clarify its particular role in the prevention or self-management of diabetes. The two main approaches to analysing language and communication are the narrative method and discourse analysis.

Narrative approaches are based on the premise that we are narrative beings (Sparkes, 2005). Narrative is fundamental to making sense of who we are, the world around us and how we communicate with each other. It is concerned with how people create meaning, how organisations make sense of the world (policy documents) and how this is linked to structures of power, and in the context and interpretation of narrative: what is said and how it is said (Finlay, 2004; Sparkes, 2005). People construct and produce their narratives in particular ways and use genres such as the romance, the comedy, the melodrama, the tragedy, the satire to describe their story (Sparkes, 2005). Much like the idea of understanding the person's context in interpretative phenomenology, Sparkes (2005) suggests that

if you know where the person is in their timeline of exposure to illness or disability then this has the potential to enhance understanding and direct appropriate intervention.

Clouston (2003) argues that narrative could be used to explore the lived experience of participants in terms of life histories, life stories and illness narratives. Creswell (2007) suggests that the narrative approach focuses on the detailed story of a single individual whereas phenomenology is more widely concerned with the meaning of their life experiences of several individuals. At the planning stages of the study it was not clear where the focus would lie and due to its exploratory nature, rather than focus specifically on the life story, a wider approach was required.

Discourse analysis emerges from social constructionism and the way in which language is used in certain contexts (Ballinger and Payne, 2000; Rapley and Flick, 2008). It looks at the way knowledge is produced through language eg medical discourse or rhetorical devices (Spencer et al, 2003). This method is useful for examining how people frame their ideas, attitudes and values through language, and can provide insight into the use of professional language and identity (Fairclough 2001; Starks and Trinidad, 2007). As part of this research question is looking at the essence of occupational therapy practice and the way the language describes this, it appears apposite to this exploration. Discourse analysis does, however, have its critics. Hammersley (2008, p.11) argues that it can be too narrowly focused on the micro data of *“discursive resources and strategies”*

rather than the wider attitudes and perspectives of the participants. The intention is to use this approach not for a micro linguistic analysis, but to examine how the language used by the occupational therapists can provide insights into the profession, its shared language and its meaning (Starks and Trinidad, 2007).

Another aspect to discourse analysis is that of metaphor-led discourse analysis (Cameron et al, 2009; Denshire, 2002; Hart, 2008). As explored in Chapter 6, metaphor is a form of language that compares two concepts. Lakoff and Johnson (1980, p.36) describe metaphor as *“principally a way of conceiving of one thing in terms of another, and its primary function is understanding”*.

An exploration of metaphor can give insight into how it is used to explain ideas or convey emotions and how people make sense of the world (Cameron, 2003; Cameron and Maslen, 2010). Metaphor analysis includes the linguistic, process and conceptual aspects of metaphor (Cameron and Maslen, 2010). Further detail of Cameron and Maslen’s (2010) process of metaphor analysis is given in the Study Design chapter. In terms of a qualitative approach, it is considered important to explore how participants use metaphor to understand their own experiences of diabetes and how it might be useful as part of occupational therapy practice.

### **8.5.3 Lived Experience: Phenomenology**

Marshall and Rossman’s (2011) third category is that of lived experience represented by phenomenological approaches, feminist inquiry and life histories. The study is concerned with the lived experience of people with diabetes and the

potential role of occupational therapy so it appears that a phenomenological approach may be appropriate for an investigation of this particular aspect. I am not looking for a specific feminist approach or a life history at this stage but instead seeking to understand the experience of living with diabetes and its impact on day to day life in all three studies.

Phenomenology is concerned with how people make sense of their experiences and attempts to make explicit that meaning in terms of significance, thinking and feeling (Finlay, 2011; Smith et al, 2009). It seeks to do justice to and understand the lived world but does not aim to categorise behaviour or generate theory (Finlay, 1999; Finlay, 2011).

Interpretative phenomenological analysis is one approach within phenomenology which seeks to interpret, and analyse, rather than just describe, that experience, where the researcher attempts to make sense of the participant trying to make sense of the experience (Smith et al, 2009). Cronin-Davis et al (2009) describe this process as exploring the participants' views and perceptions of their lived experience while also integrating the researcher's interpretation of that experience. It is inductive to allow themes to emerge rather than theory being imposed (Clarke, 2009). The interpretative approach has an emic (insider) position, to enable the participant's experiences to be central, and an etic (outsider) position to enable the researcher to make sense of this experience while grounding the interpretation in the participant's experience (Clarke, 2009). The phenomenological approach appeared to be the most compatible with the

research question and a more in-depth examination of this perspective follows to help justify this choice.

#### ***8.5.3.1 Phenomenology and philosophy***

Four philosophers in particular, Husserl, Heidegger, Merleau-Ponty and Sartre have influenced phenomenology in their own interpretations of how people make sense of their experiences (Finlay, 2011). Briefly, Husserl (1913/1962) was interested in the essential qualities of an experience and the ways in which a person could step outside of their everyday experiences so as not to try to fit that experience into pre-existing categories or theories. He suggested that it was important ‘to go back to the things themselves’, to how things do and must appear, and that things may not ‘appear’ because we think too much (Husserl, 1913/1962). This is as a result of trying to interpret what we see which, in turn, prejudices what we see. Within phenomenology Husserl’s contribution is seen as enabling researchers to understand the importance of reflecting on their own perceptions of the participant’s experience (Dowling, 2007; Smith et al, 2009). While this is clearly important, there is a certain difficulty to this approach in that the researcher’s preconceptions and knowledge are “held in abeyance” (Hamill and Sinclair, 2010, p.16) to ensure that they do not shape either data collection or analysis. However, it is questionable how aware the researcher is of their preconceptions and how possible it is to exclude all previous suppositions. This concept of bracketing has been introduced in section 8.4.1 (p.106) and is further discussed in Section 8.7 and Section 9.9.2 (p.176).

Heidegger (1927/1962) focussed on the question of existence within the particular context of time, objects, relationships and language. Interpretation needs to take account of this context (Dowling, 2007). In contrast to Husserl (1913/1962) Heidegger (1927/1962) acknowledged the researcher's preliminary understanding of the world and argued that understanding can only come about within the context of that cultural background. Hamill and Sinclair (2010) suggest that within Heideggarian philosophy the social world of the participant fuses with that of the researcher's inside view to co-construct reality. However, bracketing is still required on the part of the researcher so that unconscious assumptions are not brought to the research.

Merleau-Ponty (1945/1962) was concerned with subjectivity and embodiment and introduced the paradigm of the lived body or bodily intelligence. In this view we take our embodied self for granted until this breaks down in illness. He argued that it may not be possible to entirely share someone's experience as it is theirs (not ours) and relates to their own embodied position in the world. In this view the lived experience can never be entirely captured and is thus necessarily interpretative (Dowling, 2007; Finlay, 2011). Sartre (1943/1969) espoused that experience was a living process in that human nature was about becoming rather than being fixed in a static position. In this view each person is situated in their own particular history, geography and society. This suggests that each experience is unique to a person in that particular time (McWilliam, 2010; Smith et al, 2009).

These philosophical influences fit well with the occupational therapy approach of understanding individuals within their own context and stage of lifespan development. It also mirrors my own stance of compassionate care towards others (Gustin and Wagner, 2013; Youngson, 2012), of seeking to understand others' perspectives and interpreting their experience as fairly as possible.

#### ***8.5.3.2 Heuristic Inquiry***

Moustakas (1990), an influential phenomenologist, is concerned with heuristic inquiry, about finding the underlying meaning of an experience through a process of immersion in the topic, incubation, illumination and creative synthesis. He asserts that the self of the researcher is an integral part of the research process and the researcher experiences a new self-awareness and self-knowledge. This accords with my own beliefs as illustrated in the art work and reflexive passages in each chapter. Moustakas (1990) suggests that heuristic inquiry works best when researching something that you already have experience of (to be a framework for interpreting the experiences of others). Initially, although influenced by his ideas about creating meaning out of experience, as I do not have diabetes, I rejected this approach but I came to reconsider my viewpoint in the second stage of the study when I realised that my own professional stance as an occupational therapist would have an impact on the debate about the role of occupational therapy. In fact the phases of the heuristic research were mirrored in the use of the intuitive inquiry framework (see section 8.10). In line with the phenomenological philosophy, however, there is still a need to reflect on one's stance as a researcher to allow the new self-awareness and self-knowledge (Snelgrove, 2014).



### ***8.5.3.3 Hermeneutics and interpretative phenomenological analysis (IPA)***

I found myself drawn to the interpretative side of phenomenology. According to Smith et al (2009) three main theorists have influenced the hermeneutic position in this approach. Schleiermacher (1998) saw interpretation as a craft which included intuition. He believed that analysis could offer meaningful insights as, with its connections to a broader data set, it could bring things to the fore that might previously have been hidden. The views of Heidegger (1927/1962) centred around the presence of a person's cultural-social background. While this means that a person will have a pre-understanding of another's world it also acknowledges the importance of not bringing preconceived ideas which might influence the interpretation of that world (Finlay, 1999). Gadamer (1975/1996) was concerned about the impact of tradition on interpretation. Smith et al (2009) interpret this as the fact that our reading and understanding of the phenomenon engages with our old preconceptions which in turn can change those preconceptions which in turn changes the interpretation. Thus understanding is continually being re-examined and reinterpreted (Finlay, 1999). This requires researchers to try to make themselves open to new meanings in the data but also to be aware of biased preconceptions. It seemed to me that rather than taking one particular philosopher's stance, IPA allowed for a combination of these ideas and a need to address the issues raised in interpretation within a robust reflexive account. This is further addressed in section 8.7 and within the Study Design chapter.

#### ***8.5.3.4 Interpretative Phenomenological Analysis and Occupational Therapy***

Cronin-Davis et al (2009) argue that IPA is congruent with the values and principles of occupational therapy in terms of the process being similar to narrative clinical reasoning, and the role of the researcher mirroring that of the person-centred occupational therapist. In addition Clarke (2009) argues that IPA's recognition that meaning is influenced by contextual factors is consistent with occupational therapy's philosophy that the individual cannot be considered in isolation from their own environment. These views mirror my own stance and thus the question of understanding the lived experience of diabetes seems to fit best with this perspective. For more detail of the congruence between occupational therapy and qualitative research, refer back to section 8.3.

### **8.6 Qualitative Research, Creativity and Bricolage**

It has become clear that the phenomenological perspective of qualitative methodology appears to accord with the exploration of the lived experience of diabetes and the potential role of occupational therapy in diabetes self-management. In addition discourse and metaphor analysis enable an exploration and understanding of the metaphors that participants use and the impact of the language of occupational therapy on potential practice. Although it is usual for a researcher to take one particular perspective there is an argument to suggest that different approaches may allow a deeper exploration of the complexities of human experience (Nolas, 2011). Different approaches will enable a deeper understanding of the phenomenon in question, through enabling a number of

different interpretations, but these need cohesion (Frost, 2011). This combination of different perspectives and methods is described by Denzin and Lincoln (2005) as a bricolage and is explained further in this section.

Denzin and Lincoln (2005) suggest that with the number of new perspectives developing in qualitative research, the researcher can borrow from a number of approaches to become a 'bricoleur'. A bricoleur is defined as a 'jack of all trades' but it would be essential to ensure that the rest of this saying '.... and master of none' did not take precedence. Weinstein and Weinstein (1991) suggest three other features of the bricoleur: one who gets the job done in a practical way; one who changes the job as it is undertaken; and one who varies the job according to what is at hand. The end product is a bricolage, or what Denzin and Lincoln (2005, p.4) describe as a *"pieced together set of representations", "a solution", "an emergent construction.... which changes or takes on new forms as different methods and techniques are added to the puzzle"*.

Kincheloe (2004) sees bricolage as utilising the various approaches required as the research unfolds in order to best understand and answer the research question. Kincheloe (2004, p.2) argues that it exists *"out of respect for the complexity of the lived world"*. In his view bricolage is an active research method which creates the research process and one which acknowledges the complicated, unpredictable and complex interaction between the researcher and the data. Bricoleurs step back from the research process to allow for other interpretations and to avoid reductionism (Kincheloe, 2004). In many ways this

mirrors the concepts of bracketing discussed earlier, in which the researcher attempts to avoid their own assumptions and be open to other interpretations (Ahern, 1999). Indeed Berry (2004) argues that using only one methodology to answer a research question would only partially answer that question.

These views acknowledge the difficulties in making sense of qualitative data and finding new insights (Klag and Langley, 2013). Qualitative methodology is not a linear, sequenced process but a dynamic and often 'messy' practice (Lambotte and Meunier, 2013) and this is reflected in the circular nature of the intuitive inquiry process (Anderson 2011) of this study. Lambotte and Meunier (2013, p.86) argue that researchers should embrace this messiness and that bricolage, which they see as "mixing, improvising, engineering and risk taking", enables connections to be made and meanings to be produced. Bringing many different perspectives to the research process through bricolage can lead to better understandings (Rogers, 2012; Wibberley, 2012).

It can be argued that the concept of bricolage also reflects the nature of occupational therapy and thus is congruent with the aims of the study. Gobbi (2005) argues that nurses draw on the elements and tools of their trade (bricolage) to come up with solutions for their clients, often adopting the role of bricoleur as described by Weinstein and Weinstein (1991). This avoids a reductionist approach to complex problems (Warne and McAndrew, 2009) and reflects the fact that responses to situations vary depending what is to hand. Gobbi (2005) suggests that this bricolage enables nurses to make sense of and

respond most appropriately to their clients, while often managing potentially competing and overlapping perspectives. The same could be said of occupational therapists who also draw upon a 'bricolage' of creative, artistic, theoretical, intuitive and practical tools when working in the dynamic and 'messy' nature of practice.

The bricolage of approaches in this study include phenomenology, discourse analysis and metaphor analysis. In addition there is also an element of creativity that has become woven into the study in the form of mixed media artwork, as shown at the start of each chapter. Smith et al (2009) argue that interpretive phenomenological analysis lends itself to innovative and creative approaches both in the process of the research and also in reflexivity. This latter concept is explored in more depth in the following section but, in terms of process, the use of mixed media artwork enables a way to explore all the different perspectives and challenges plus the views of the participants and the researcher. The use of creativity is also consistent with the philosophy of occupational therapy (Blanche, 2007; Dickie, 2011; Perrin, 2001; Reynolds and Prior, 2006; Riley, 2011; Schmid, 2004) and has become a recognised approach in qualitative research (see Davidson, 2011; Kay 2013; Lapum et al, 2011; Marshall, 2007; McNiff, 2011).

The bricolage of approaches is not without its critics. Kincheloe and McLaren (2005, p.316) raise the issue of "*theoretical coherence and epistemological innovation*" which may well mirror the argument of a bricoleur being the 'master of none'. Although they argue that the bricoleur seeks a range of approaches to

find new knowledge so as not to get stuck in potentially more reductionist research methods, there is a danger of ending up with a disparate final product. Hammersley (1999) questioned the bricoleur metaphor due to his concern about the use and acceptance of ideas that might be at cross-purposes. His own metaphor was that of boat building which, he argued, would not allow the design of one part of the boat as a canoe and another as a steamboat (as per bricolage) because the boat would sink. Hammersley (1999) argued that research, like ships, needed working parts that fit together and a sense of origin and destination. His metaphor allows for many ships heading in a variety of directions but with no interchange of parts. In other words there needs to be coherence. Later he interprets bricolage as “*do it yourself*” and the bricoleur as a “*handyman*” which he says implies second-best in contrast to doing research with the appropriate tools and experience (Hammersley, 2008, p.138). Again this appears to suggest that using different strands could take the researcher far away from the original line of enquiry of producing knowledge about the world through careful argument. While these issues are acknowledged, a way to ensure coherence was sought so that these aspects of the research process could be unified in a framework. This will be discussed further in section 8.10 Intuitive Inquiry.

## **8.7. Qualitative Research, Reflexivity and Bracketing**

Another aspect of qualitative research which requires consideration is that of reflexivity. Within qualitative research whichever perspective (or combination of approaches) is taken there is a need for the researcher to reflect on their impact

on the research. This is a process known as reflexivity (Guba and Lincoln, 2005) which considers the role of the researcher pre-research (design stage), during data collection and analysis.

Clearly it is not possible for the researcher to report on the experiences of others with objectivity (Denzin and Lincoln, 2005). Each researcher views the life of another through the lens of language, gender, social class and professional standing. Although it has been acknowledged that the subjectivity of qualitative research is a strength in itself (as opposed to the supposed objectivity of quantitative research), there is still a need to acknowledge and potentially restrain pre-conceived judgements, assumptions and theories (Bishop and Shepherd, 2011; Finlay, 2011; Pyett, 2003). This is achieved through a process of bracketing and reflexivity, as introduced earlier in this chapter.

Holloway (2005, p.279) defines reflexivity as *“the interaction of the researcher with the research and the participants ..... it implies self-awareness, critical evaluation, and self-consciousness of their own role on the part of the researchers”*. Finlay (2009) suggests using rich descriptions, sometimes evoked through poetry or metaphor, to interrogate both the data and her own assumptions as an approach to reflexivity.

Bracketing is seen as putting to one side the researcher’s habitual ways of thinking or seeing in order to engage with the views of the participants (Drew, 2004; Rolls and Relf, 2006; Snelgrove, 2014). It is considered that this should be

attempted from inception to completion of research (Drew, 2004) but there is criticism that this is often done in a simplistic or perfunctory manner (Fischer, 2009). How bracketing is achieved is a much contested debate, although it is considered to be closely linked to reflexivity (Converse, 2012; Snelgrove, 2014). Through a process of reflexivity the researcher monitors their role and approach and draws meanings from the data with an open mind (Snelgrove, 2014). It is not clear whether merely being aware of one's prejudices and pre-suppositions is enough (Converse, 2012). Indeed it is argued that bracketing is impossible because habitual ways of thinking and seeing are based on one's life experience, which cannot be completely put to one side (Allen-Collinson, 2011; Converse, 2012). Allen-Collinson (2011, p.56) suggests that this position is "*idealist, unattainable and untenable*" because the researcher is always situated in the world and thus cannot be uncontaminated by their own context. Paradoxically, having preconceptions as a researcher might actually alert the researcher to identify issues or themes in the data (Ahern, 1999). In addition Hamill and Sinclair (2010) argue that researchers can *unconsciously* bring assumptions to the research and thus may be unaware as to how this is influencing the information and experiences that their participants bring to the process.

Clearly there may be differing levels of self-awareness amongst researchers and many assumptions and deeply held beliefs can be hidden. While it is clearly difficult to 'absolutely' bracket, there is merit in engaging in reflexivity as far as possible in order to be questioning, critical and open to the research process (Allen-Collinson, 2011). For my own part it was important for me to be very clear



that I was being true to the perspectives of the participants and many hours were spent considering the process of the research study, in particular the analysis, through the use of mixed media artwork, mirroring Finlay's (2009) rich descriptions. The examples of the art work and the reflexive comments in each chapter aim to demonstrate my awareness of where I am in the research study process (Green and Thorogood, 2009).

## **8.8 Intuitive Inquiry as a Framework for the Study**

As has been argued a number of approaches and a combination of approaches could be used in qualitative research to help answer the research question. Although combining approaches may potentially be problematic, it has the advantage of understanding the research question through a range of interpretations (Nolas, 2011). This section considers how all the parts of the study could be drawn together in a framework that avoids the potential pitfalls of multi-method muddying of the waters (Hammersley, 2008) and which remains true to the overall phenomenological perspective. The framework that best meets these needs is that of intuitive inquiry (Anderson, 2004).

Intuitive inquiry has been described as *"a search for new understandings through the focused attention of one researcher's passion and compassion for oneself, others, and the world"* (Anderson, 2006, p.2). Anderson (2004, p.307) describes it as a qualitative hermeneutical approach, combining intuition with *"intellectual precision"* and one that includes creativity and deep reflection. The framework

provides a structure around which elements of this study can fit cohesively.

There are five cycles all of which include both analytic and intuitive processes,

1. Clarifying the Research Topic
2. Preliminary Interpretive Lenses
3. Collecting Data and Preparing Descriptive Reports
4. Transforming and Revising Interpretive Lenses
5. Integration of Findings and Theory Building

(Anderson 2011, p.249)

These cycles are described in Box 1 (p.131) and more detail is explained in chapter 9 Study Design. Figure 14 (p.132) shows how the cycles can incorporate the different perspectives of qualitative methodology.

As has been previously discussed in this chapter, what was important to me in this study was to be able to take a number of perspectives to explore the research question, which were in keeping with and honoured both the needs of the participants and the core values of occupational therapy. Thus the perspectives of heuristic phenomenology, interpretative phenomenological analysis, metaphor and discourse analysis, creativity and mixed media artwork are all present.

Figure 14 indicates how I see the framework of intuitive inquiry bringing all the threads of the study together in a cohesive way. Each of the three studies is colour coded. On the extreme left are the cycles of the intuitive inquiry (each cycle of each study is detailed in the Study Design chapter). The blue arrows

show how the three studies are linked and the central green sections indicate the links between the intuition, creativity, reflection and perspectives of phenomenology and metaphor and discourse analysis. Each cycle is described in detail in Box 1 below.

#### Cycle 1: Clarifying the research topic

This is about the researcher understanding why they have chosen their topic and exploring their pre-understandings of the topic. Some researchers use images, dramas or texts in relation to the topic, to engage with this material and record their insights.

#### Cycle 2: Preliminary interpretative lenses

Here the researcher reflects on the topic in the light of the existing literature and starts to explore understanding of the topic before gathering data. It is similar to cycle 1 but this time the texts are more theoretical. The aim is to clearly identify the particular research topic but also be aware of assumptions and personal values.

#### Cycle 3: Collecting data and preparing descriptive reports

In this cycle the researcher identifies the source of the data, selects criteria, collects the data, prepares to analyse the data. Most intuitive inquiry researchers collect this data in form of interviews. Anderson's own metaphor for this stage of the process is "hovering low like a hummingbird over the data and relaying what you see from that vantage point" (Anderson, 2011, p.254).

#### Cycle 4: Transforming and revising interpretive lenses

Here the researcher looks at the data gathered and compares it with cycle 2, revisiting assumptions, reflecting, looking at how much the data collection might have influenced the researcher's stance, evaluating what is different, being aware of any intuitive breakthroughs, bringing ideas together and documenting insights.

#### Cycle 5: Integration of findings and theory building

In this cycle the researcher presents the findings from cycle 3, and integrates this into the literature of cycle 2 as modified by cycle 4. The researcher decides what is significant about their particular study in the light of that literature. Using reflection and reviewing previous reflection, the researcher stands back from the whole thing to bring all the cycles together, "as though drawing a larger hermeneutical circle" (Anderson, 2011, p.255) around the study.

**Box 1 Cycles of Intuitive Inquiry**

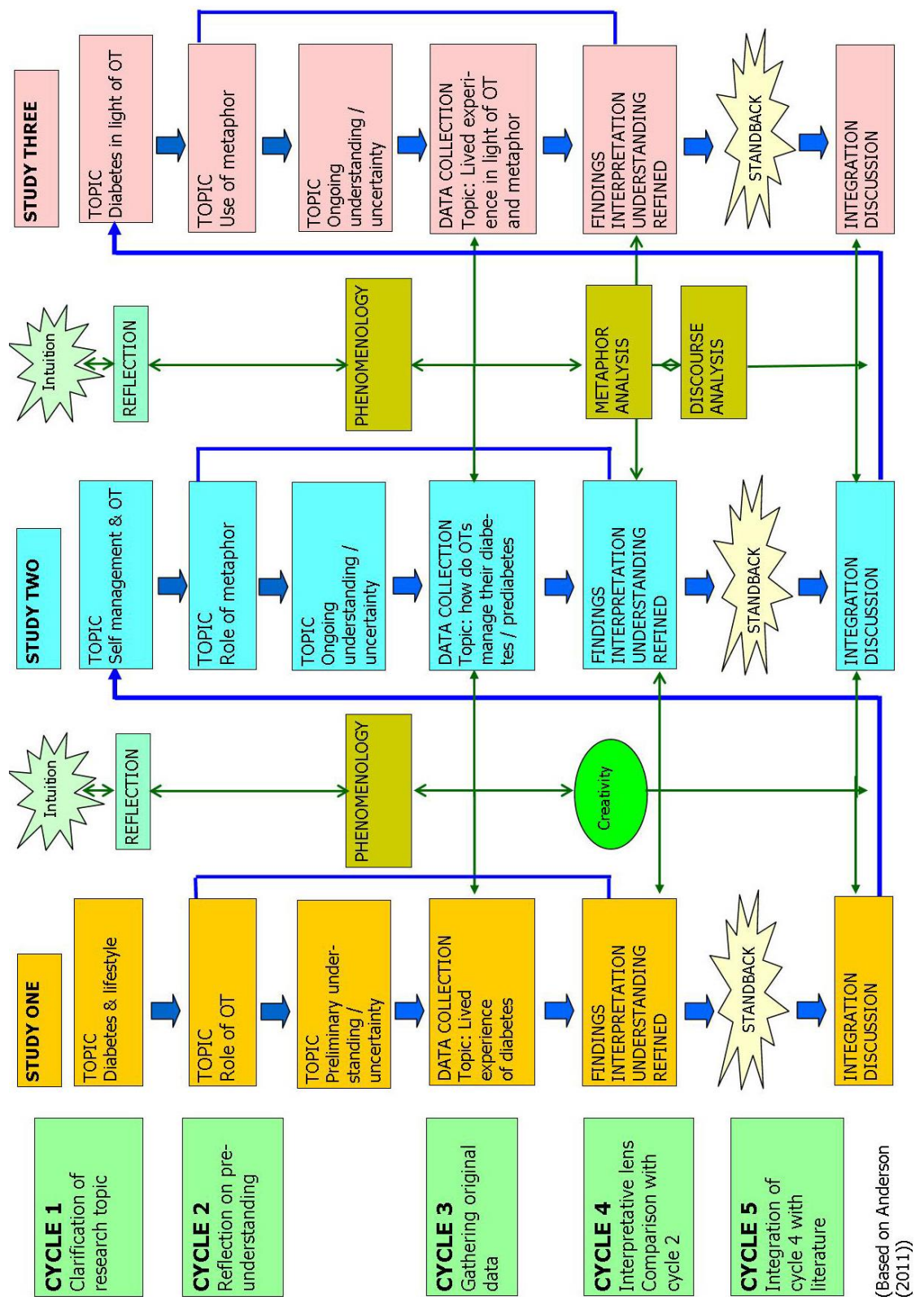


Figure 14 Intuitive Inquiry process for the three studies

## **8.9. Summary**

This chapter has explored my own ontological and epistemological stance, the compatibility between occupational therapy and qualitative research, the differences between qualitative and quantitative research and debated some of the issues of quality. It has looked at definitions and different perspectives in qualitative research; investigated the concept of bricolage and considered the reflexive process. It has drawn these threads together in a cohesive framework of intuitive inquiry. In summary the defence of the methodology lies within its epistemology, its potential and pragmatism (Green and Thorogood, 2009).

From an epistemological viewpoint qualitative research is largely about understanding the perspectives of others and recognising how reality is constructed. In researching how occupational therapy might enable people to self manage their diabetes, it is important to first examine people's experience of this condition to ensure that the occupational therapy is situated in that world.

Qualitative research has the potential to add to the evidence base by looking at areas that more quantitative experimental 'deficit' models of clinical research cannot address eg the meaning of diabetes to individuals, the social processes by which they make decisions about their diabetes, about the impact of interactions with healthcare professionals on behaviour and beliefs. Similarly from a pragmatic point of view qualitative research has the potential to allow for a range of viewpoints, and being alerted to these can help with approaches to intervention.

A pluralistic methodology, or a bricolage of perspectives and approaches, has been proposed to enable a deeper understanding of the complexity of living with diabetes and the potential occupational therapy approach. It is felt that there is cohesion within this bricolage which reflects the philosophy, core skills and core beliefs of occupational therapy and the compatibility between occupational therapy and qualitative research. The next chapter will explore the specifics of the Study Design. The following reflection considers the progress that has been made in contemplating the methodology.

***Reflections on progress in methodology:***

*An internal debate in my head around reading about and doing phenomenology, and whether there's a 'right' approach. In some senses it feels like IPA is what I'm doing, exploring the lived experience in whatever way the participants wanted to talk about it. But then I read Todres (2005). His description seems much more focused eg as if I was asking about a specific encounter with eg a healthcare professional. I can see that that would fit much more readily with his description of phenomenology but not with what I've got so far. So I don't think this has been my approach at all. I have gone for the semi structured interview and let whatever came from that - which seems reasonable to me. But Todres might be the way forward in the future if for instance a theme that was coming out of the data was around encounters with healthcare professionals - which so far all 3 participants have mentioned. So bearing that in mind what approach am I going to use to analyse the data? Do I stop after the 4<sup>th</sup> participant to restock and make a decision on that? Is this something about the 'methodology' of the naïve researcher, seeing what happens and drawing out themes from that? Will it end up being a process of elimination? And does this have a positive aspect by avoiding reductionism?? Or can it just result in a methodologically unsound study?? (March 2013)*



**Figure 15 Coding**

*I created a pattern on gessoed cotton, using watercolour pencils to represent the raw data. I then cut this into pieces and glued the pieces onto coloured foam. Each of the foam squares was then hole punched and attached with treasury tags. The original pattern represents the raw data and cutting it up represents the coding. Attaching the pieces to the foam represents building themes. The treasury tags allow an almost endless rearrangement of the data into themes. This was an exploration of how the pieces can be rearranged or the shape of the whole can be varied to show the possibility of a number of different themes. The data will essentially still be in boxes whatever the final layout is. This led me to ponder whether there is a new meaning or interpretation and whether it is greater than the original or just different.*

## **9.0 Study Design**

### **9.1 Chapter Outline**

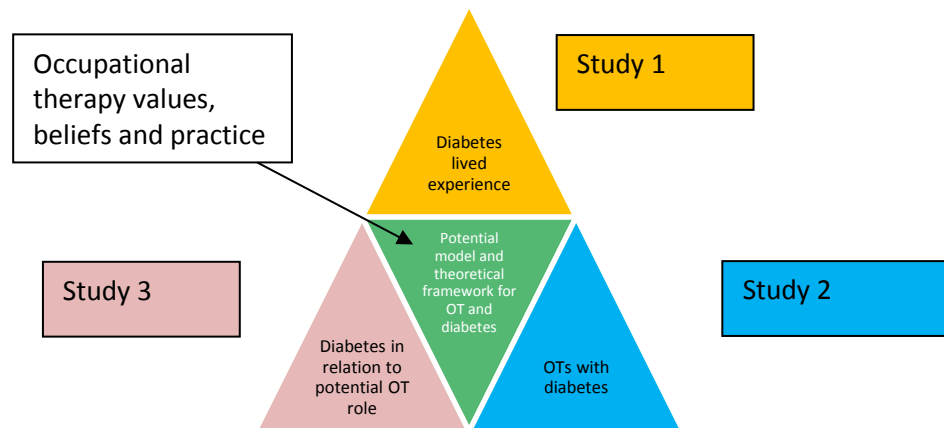
The aim of this chapter is to describe the study design to complement the Methodology chapter and give more detail about the qualitative nature, approach and design of this study. This chapter summarises the initial approach developed from the methodology and describes the changing focus of the study into its three stages. It discusses, epistemology and approach, recruitment and sampling, data collection, ethical considerations and the qualitative data analysis methods used. Following discussion of the design of the three studies, the credibility and trustworthiness of the research is considered. The chapter summary includes a decision flow diagram, showing a time line of the decisions and changes made in the light of the three studies.

### **9.2 Epistemology and Approach**

The study design is based on a pluralistic methodology, or a bricolage of perspectives and approaches, to enable a deeper understanding of the complexity of living with diabetes and the potential occupational therapy approach. As discussed in the Methodology chapter the overall framework for the study is that of intuitive inquiry (Anderson 2004, 2011). The bricolage includes a blend of interpretative phenomenological analysis (Smith and Osborn, 2007; Smith et al, 2009), heuristic inquiry (Moustakas, 1990), metaphor analysis (Cameron, 2003; Cameron et al, 2009; Cameron and Maslen, 2010) and creative mixed media. These aspects will be discussed further within each study. Figure



16 gives an overview of the research study and how the separate studies fit together.



**Figure 16 Overview of the research study**

The potential theoretical framework for occupational therapy and diabetes is at the centre of all three studies, which includes occupational therapy values, beliefs and practice. The design of each study will be discussed separately. Initially consideration is given to the recruitment and data collection, followed by a discussion of the ethical aspects of the research.

### **9.3 Recruitment and Sample Size**

Ritchie et al (2003) suggest that the sample size needs to be relatively small to do justice to all the information obtained and thus only works well if ‘good’ purposive sampling has taken place, where the participants are information rich (Bowen, 2008). This entails that the sample both represents and has salience to the research topic and is diverse enough to allow for different characteristics to be identified (Hammell, 2002; Ritchie et al, 2003). The sampling of this study

strove to meet these criteria by focussing on different ages, geographical locations, type of diabetes and length of time since diagnosis.

While it is not possible or desirable to put numbers on a sample size (O'Reilly and Parker, 2013), Green and Thorogood (2009) argue that little that is new emerges after approximately 20 people have been interviewed. Research by Mason (2010) on sample size in PhD studies revealed that with those with phenomenology in their approach, all had at least six participants, as suggested by Morse (1994) and two thirds met the range of 5-25 as suggested by Creswell (1998). While the appropriate number of participants (n=22) in this study falls within the recommended size, it is important not to go for a 'quota' of sample size but to sample until saturation is reached.

O'Reilly and Parker (2013, p.191) suggest that the concept of saturation has become the "*gold standard*" to measure sample sizes but argue that a certain amount of pragmatism needs to be considered to ensure an adequate sample size. This depends on the topic and the available resources. Hammell (2002) argues that this cannot be precisely determined in advance because it is not possible to know when recurrence of themes or issues will occur. Generally saturation is seen as the point at which the data set is 'complete', when there is replication and no new insights are being added (Bowen, 2008; Green and Thorogood, 2009; Ritchie et al, 2003). However it could equally be argued that there is always potential for new data to emerge as each individual's experience is different (Strauss and Corbin, 1998).

Bowen (2008) suggests that it needs to be made clear how saturation was achieved and to substantiate this with clear evidence, in other words it is not enough to say that saturation was reached (Bowen, 2008; Caelli et al, 2003). There is no formula (Bowen, 2008) but O'Reilly and Parker (2013) suggest that saturation can be indicated by being transparent about the depth of the data.

Within this study, saturation is believed to be demonstrated by the thoroughness of the sampling, the transparency of the data analysis and the adequacy of the findings. In addition, it is believed that the findings and discussion show the links between themes, consistency and completeness to ensure that the research question is "*convincingly answered*" (Whittemore et al, 2001, p.532).

## **9.4 Data Collection**

Interviews are considered to be the most commonly used method in qualitative research (Nunkoosing, 2005; Sandelowski, 2002). However it is acknowledged that it is never absolutely certain whether the interview accesses true subjectivity or whether participants use the interview opportunity to construct certain identities (Bishop and Shepherd, 2011; Hammersley, 2008; Nunkoosing, 2005) or to emphasize or withhold some aspects of the topic (Mauthner and Doucet, 1998). Hammersley (2008) states that criticism of the interview goes so far as to say that the only thing interview data reveal are what goes on in a particular interview. It is also argued that there is a certain element of performance on the part of the researcher, to come over as professional and that it is not possible to be certain how the researcher's appearance, behaviour, assumptions, values or

beliefs during an interview shape the data collection (Bishop and Shepherd, 2011). Hammersley (2008) suggests that critics of interview believe this 'contaminates' the interview.

It is evident that there is much room for bias (consciously or unconsciously) in the interview. However Beer (1977, p.125) argues that the "*interviewer effects*" are at the heart of the interview – not that the researcher is trying to influence but that in the creativity of the interview the attempt is made to understand the participants' experiences. He suggests that it is undesirable to separate the researcher from the interview and that it is the sharing of the experience that makes discovery possible.

Being aware of this, reflection before and after interviews was undertaken, using interview checklists based on Legard et al (2003) and Taylor (2005). Questions were changed in response to new themes or issues (Hammell, 2002). Awareness of the effect on participants was noted. Interviews appeared to have a therapeutic benefit in giving participants the opportunity to be listened to (Kvale, 1996) and all participants expressed their thanks for this opportunity. Participants, especially in Studies 2 and 3 were asked to prepare for the interview to enable them to put their thoughts in order first to enable understanding in the interviews (Hammersley, 2008). Interviews were also interactive in the sense that participants were given the opportunity to ask questions. This allowed for opposing viewpoints (Hammell, 2002), which was particularly relevant for the sharing of occupational therapy themes in Study 2.

## **9.5 Ethical Considerations**

Protecting the rights of participants from risk or harm is fundamental to the research process (DePoy and Gitlin, 2011; Ryan et al, 2009). This section considers issues of research procedure regarding informed consent and confidentiality, and then discusses wider concerns of potential exploitation and power. In view of the fact that this study was concerned with maintaining the values of the occupational therapy profession (see Chapter 8.3), adherence to the Code of Ethics and Professional Conduct (COT, 2015) was also considered essential.

### **9.5.1 Informed Consent**

To ensure participants' understanding and expectations of the study, disclosure of the aims and procedures of the study and the scope of involvement was set out in participant information sheets (PIS) and individual consent forms (Cohn and Lyons, 2003; DePoy and Gitlin, 2011). Examples of the PIS and consent form for Study 2 are given in Appendix 4 and 5 (the format of PIS and consent form for Studies 1 and 3 are the same apart from titles and a different emphasis in the 'About the study', 'Why have you asked me to take part' and 'What will I be required to do' sections of the PIS to reflect each particular study). It is recognised that describing the aims in the PIS can risk introducing a perspective that might bias participants' responses (DePoy and Gitlin, 2011). However this was balanced against the need for disclosure by using general statements about the direction of the study. Disclosure included explanation of the purpose of the

study, expectations of the interview process and any preparation required prior to the interview. For example in study 2 participants were asked to prepare a metaphor for their experience of diabetes prior to the interview. Written consent was obtained just prior to each interview. Recognising that participants might change their mind about what was said in the interview, the transcripts were made available to participants to remove or change what was said (Nunkoosing, 2005). In order to prevent possible upset from disclosure about their experiences of diabetes, it was suggested to participants prior to interview that they may wish to have someone nearby who could offer support and participants were informed that they could decline to answer questions. Although every effort was made to enable participants to feel comfortable and safe (COT, 2015), it is acknowledged that intrusion into people's lives could cause distress (Alderson and Morrow, 2004). Participants were informed of their right to withdraw at any time and that participation was entirely voluntary (DePoy and Gitlin, 2011). No participants withdrew and all participants reported that they had enjoyed the interviews and the opportunity to talk about their diabetes.

### **9.5.2 Confidentiality**

In order to ensure that participants could not be connected with what was recorded and reported, confidentiality was maintained throughout (DePoy and Gitlin, 2011). This was achieved in the following ways. For anonymity participants were each given study codes and pseudonyms. In the case of occupational therapists in study 2, it was recognised that the occupational therapy population is small enough for professional career details to be linked to individuals and thus these were summarised collectively. All references to

named places or organisations were removed or given pseudonyms (DePoy and Gitlin, 2011). It is, however, recognised that the use of pseudonyms and anonymity to disguise the participants, while meeting ethical standards, may also be disempowering. The process means that participants are no longer discrete individuals and potentially takes away ownership of their thoughts and experiences (Mauthner and Doucet, 1998). Other issues around power are discussed below.

### **9.5.3 Power**

By its nature the whole research process is one of unequal power (Legard et al, 2003; Mauthner and Doucet, 1998). The researcher retains the power over the process, the data collection, the structure of the interview schedule, the analysis and the reporting (Cohn and Lyons, 2003; Mauthner and Doucet, 1998; Nunkoosing, 2005). However Beer (1997) suggests that interviews are creative and complex events in which the intersection of the researcher and the participant 'creates' the data (rather than the data being 'picked' from the head of the participant) and thus both the researcher and the respondent have an effect (Beer, 1997), although this effect may not of course be equal. Nunkoosing (2005, p.699) suggests that the power shifts in the interview from the participant as the "*privileged knower*" to the interviewer as the expert researcher. Hammell (2002) goes so far as to propose that researchers see themselves as having knowledge (superior power) while the participants have beliefs (inferior). Efforts to mitigate this imbalance and to minimise potential harm or distress were made by establishing trust and rapport early on in the interview process through active

listening, endeavouring to ensure that the participants were at ease and by conducting interviews in a place of the participant's choosing (Ryan et al, 2009).

In terms of the analysis it was important to ensure that the participants' voices were prioritised and not lost in the views of the researcher (Bishop and Shepherd, 2011; Mauthner and Doucet, 1998). Prioritising those voices, while at the same time reducing the data into a manageable form, is not without difficulty (Mauthner and Doucet, 1998). This was addressed through continuous reflexivity (Bishop and Shepherd, 2011) and through extensive use of the participants' words in the findings, although it is acknowledged that these are necessarily out of context of the whole story (Mauthner and Doucet, 1998). Reference is made to this in description of the study design stages (see Tables 3, 4 and 8). Mauthner and Doucet (1998) also suggest that the data analysis stage is disempowering as participants have little control over how the analysis is carried out. This was moderated to a certain extent by returning the transcripts and then a report on the findings to the participants at each stage where they were given a choice of whether to comment, agree or, disagree. Further discussion of this issue appears in section 9.9.

All of these considerations formed part of the applications for formal ethical approval that were granted by the University of Cumbria (ref 12/13 and 13/11).



## 9.6 Study 1 Diabetes Lived Experience

Figure 17 summarises the design of study 1. The cycles of the intuitive inquiry process (Anderson, 2011) will be discussed in turn, highlighting both the procedure and the opportunity for me to examine my own role in the research process, as summarised in the boxes related to reflection, lens and breakthrough.

It will be noted in Figure 17 (and in the subsequent Figures 18 and 19 for Study 2 and Study 3) that the green boxes in the centre of the diagram change from reflection to reflexivity. This demonstrates the reflection-reflexivity continuum as described by Finlay (2002a, p.532) whereby the initial reflections in cycle 1 and 2 denote *“thinking about”* and the later reflexivity of cycles 3, 4 and 5 are concerned with a more *“immediate, continuing, dynamic and subjective self-awareness”* (Finlay, 2002a, p.533) in relation to the data collection, analysis of findings and final thoughts about my impact on the study.

### 9.6.1 Study 1 Cycle 1 and 2 Clarifying the Research Topic

Clarifying the research topic for this study was based on the literature, previously reviewed in Chapters 3, 4 and 5, in which it became clear that self management approaches in diabetes were concerned with changes to lifestyle but that there was not a clear role for occupational therapy. As discussed in the Introduction my first thoughts about this were simplistic and influenced by the political and ideological agenda of medicine and public health (Bishop and Shepherd, 2011).

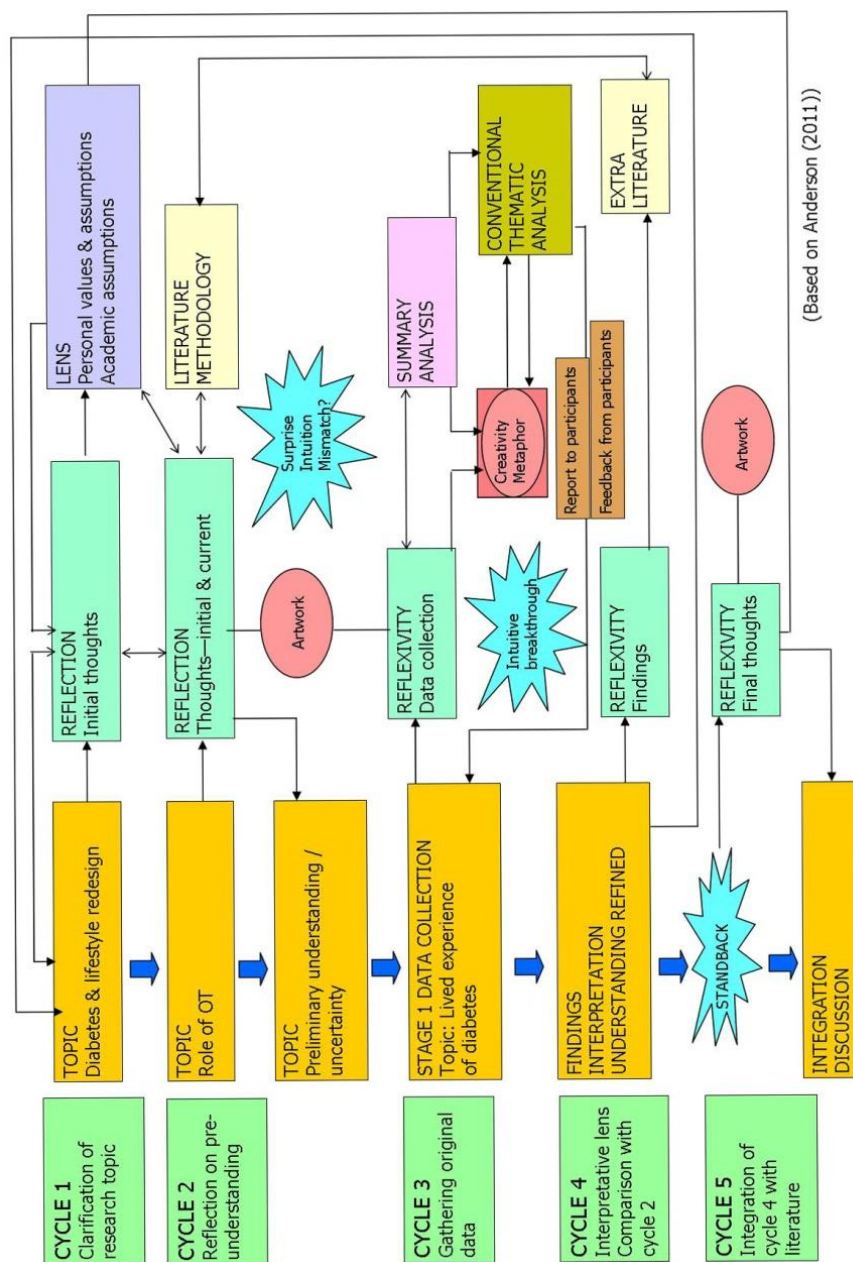










Figure 17 Intuitive inquiry process for Study 1

KEY TO FIGURE 17			
	Cycle		Colour represents study 1
	Stages through cycle		Intuitive breakthrough moment
	Reflection and reflexivity		Artwork describing process
	Forward / back movement		Cross-over between artwork and metaphor

Through repeated reflection on the literature, the focus on self management in diabetes became based on the life context, rather than the medical aspects of this condition, and the aim became an exploration of the lived experience to understand how occupation impacts on and is impacted by diabetes.

### **9.6.2 Study 1 Cycle 3 Data Collection**

As the initial focus was designed to understand the issues and reality of living with diabetes, a phenomenological research design was chosen, which offered both the philosophical and practical tools to explore this lived experience (Finlay, 2011). In line with interpretative phenomenological analysis (IPA), a purposive, convenience sample of people was sought (Smith et al, 2009). A purposive sample ensures the deliberate selection of participants with particular characteristics to enable exploration of the topic (in this case living with diabetes) but also a diversity of experience to enable investigation of those characteristics (Ritchie et al, 2003). A convenience sample was chosen for ease of access to enrol participants who met the purposive criteria (DePoy and Gitlin, 2011). Although there is potential for bias (Ritchie et al, 2003), this was mitigated by selecting a range of ages, types of diabetes and length of time with the condition.

In line with the discussion on saturation (section 9.3 above) it was anticipated that 5 to 10 participants would be recruited who met the study criteria of being adults over the age of 18 who were information rich i.e. able to articulate their feelings and experiences of diabetes (type 1, type 2 or pre-diabetes) and who did not have dominant coexisting health conditions which might detract from the

focus of the study. Participation was entirely voluntary. Participants were recruited initially by word of mouth. I talked about the study widely with colleagues and acquaintances and received offers from people who believed they knew others who might wish to take part in the study. Potential participants were approached by these third parties to enquire whether they wished to participate. Where this was agreed, I then followed up the invitation by telephone or email to discuss the study further and to ascertain that they met the study criteria. In this way seven participants were recruited from the North West of England. As discussed in the section on ethical considerations, participants were sent information sheets and informed consent was gained prior to each interview.

Data were collected using digitally recorded individual, semi-structured interviews of 60-90 minutes. Interviews are seen as the most powerful way to access the lived experience of a person (Fontana and Frey, 2005; Nunkoosing, 2005) and offer the opportunity to discover the differences between the world views of the researcher and the participants (Beer, 1997). They are commonly used in phenomenology (Smith et al, 2009) and intuitive inquiry (Anderson, 2011).

Three main types of interview have been identified: structured, semi-structured and unstructured (Ryan et al, 2009). In structured interviews the interview schedule has a fixed set of questions allowing no deviation, while unstructured interviews are non-directive with no specific framework of questions (Ryan et al,

2009). Semi-structured interviews, while focussing on predetermined topics, allow for more flexibility through the use of open-ended questions in response to the participants' answers (Todd, 2006). It was felt that this method of data collection best fitted exploration of the research question and was utilised to allow participants to talk about their own lived experience of diabetes. All interviews were conducted face to face to enhance understanding of what was being said through observation of non-verbal cues, and began with easy non-threatening questions such as demographic information (Ryan et al, 2009). In order not to make any assumptions about their experiences (Turner, 2010) participants were then asked one open-ended question: 'Can you describe what it is like to live with diabetes?'. Depending on the answer to this initial query, subsequent questions were asked which allowed for further exploration or explanation (Legard et al, 2003; Smith and Osborn, 2007). Interview schedules for all three studies can be found in Appendix 3.

While transcribing, reference was made to interview checklists (Legard et al, 2003; Taylor, 2005) to reflect on my own skills as an interviewer, particularly looking at potential traps and pitfalls eg how directive the interview style was, looking at silences, probing questions, or any leading questions and these were noted in the fieldwork diary, to be considered in future interviews. Participants were sent copies of their transcripts for checking and to give them the opportunity to make any changes (Caelli, 2001). Participants acknowledged receipt of their transcripts. One stated that she did not wish to read hers and none elected to make changes.

### 9.6.3 Study 1 Cycle 4 Interpretative Lens

Strategies in line with suggested methods for general thematic analysis (Braun and Clarke, 2006) and phenomenological analysis (Smith et al, 2009) were employed to start to structure the data. In the interests of transparency and honesty (Dickie, 2003; Savin-Baden and Fisher, 2002) detail is added to describe the interpretation of the data beyond the stages described in Table 3. While Table 3 shows the more traditional stages of the process of data analysis, the right hand column indicates the thinking, reflection and creativity that ran parallel to this process.

Finlay (2011, p.229) suggests “*dwelling*” with the data and asking questions of it. In order to find the meanings in the interview transcripts, and based on IPA strategies of the participants’ attempts to make sense of their experiences (Smith et al, 2009, p.79), my analysis began with the following broad questions:

- What were the participants describing about their experience of diabetes?
- Were there similarities and differences between participants?
- Was there a difference between different types of diabetes?
- Did length of time with diabetes help or hinder people’s ability to manage?
- What emotion was being displayed?
- In what way were people supported with their diabetes?
- What was stopping people manage?

Step	Description	Reflection and Intuition
1	Transcripts typed	Reflective diary account about areas of significance for each interview, asking questions
2	Checked against recording	
3	Sent to participants for checking	
4	Further reading and rereading of transcripts (initial noting)	Mixed media art work – building meanings, dipping a toe,
5	Coding: line by line action codes for each transcript	Art – scratching the surface, illuminated thoughts, coding
6	Emergent themes – hierarchy of ideas	Mind maps
7	Forcefield analysis and other representations	Reading Art - Headspace
8	Back to guidance re analysis – memo writing	Art – immersion, coming up for air, mining the data,
9	Connecting themes across the participants	Art – grappling with the data
10	Felted metaphor	Art – felting; intuitive breakthrough
11	Reviewing and refining themes in relation to metaphor	Reflective diary
12	Report with picture of metaphor to participants	Reflective diary on impact of art, response to participants' feedback Art – weavings on writing
13	Response from participants	
14	Summary and influence on study 2	

**Table 3 Process of Data Analysis Study 1**

Transcripts were printed out with wide margins (Smith et al, 2009). Several readings of the transcript data were made to identify patterns and themes, and initial codes were applied based on the broad questions (Smith et al, 2009). The codes were summarised under 4 emergent themes of relationships with healthcare staff; defining self; world view (a life worth living) and taking control. It was felt that this did not adequately explain the complete lived experience and thus a different perspective was sought.

Further reading of the data suggested that there appeared to be both driving and resisting forces in participants' ability to manage their diabetes and thus a force field analysis was utilised both on an individual and collective basis to help make sense of the data. A return to the literature on methodology suggested that there was a danger of forcing the data into existing concepts or theories

(Charmaz, 2006) and thus these perspectives were put to one side, the transcripts were once again studied and memos written describing the themes in more detail (Smith et al, 2009).

At the same time these stages of the analysis were also contemplated and described separately in mixed media art work, congruent with my preferred learning style of thinking visually (See Appendix 2 and the art works described at the beginning of each chapter). Although it is not common within qualitative analysis, there is evidence to suggest that visual art enables time for thinking and problem solving (Allen, 1995; Dickie, 2003; Lydon, 1997) while at the same time creating new insights and perspectives (Dadds and Hart, 2001; Marshall, 2007). Reflection on the data, along with the analytic process, led to the intuitive production of a felted metaphor to represent the findings as a more 'whole' complete piece to show the relationship between the different themes (Potter, 2001). Themes were then reviewed and refined in relation to the felted metaphor to ensure coherence and credibility of the interpretation (Smith et al, 2009).

A photograph of the felted sea metaphor with a traditional table of the themes and the relationships between them is shown in Chapter 10: Study 1 Findings (p.186). A photograph of the metaphor and an explanation of the findings were sent to participants for their review and comment. Those that responded confirmed that both the metaphor and the findings made sense and encapsulated their experience. In addition some participants commented further



on their diabetes lived experience in response to the metaphor. Their feedback is considered in the discussion section of Chapter 10.

#### **9.6.4 Study 1 Cycle 5 Integration**

Integration of cycle 4 with the literature appears in the discussion in Chapter 10. Decisions made as a result of Study 1 led to consideration of further exploration of metaphor and, in the light of the lived experience of diabetes, further examination of that lived experience from the point of view of occupational therapists with diabetes was sought.

### **9.7 Study 2 Occupational therapists with diabetes**

Figure 18 summarises the intuitive inquiry process for Study 2. As with Study 1 the cycles of the process will be discussed in turn, highlighting both the procedure and the opportunity for reflection on the research process.

#### **9.7.1 Study 2 Cycle 1 and 2 Clarification of the Research Topic**

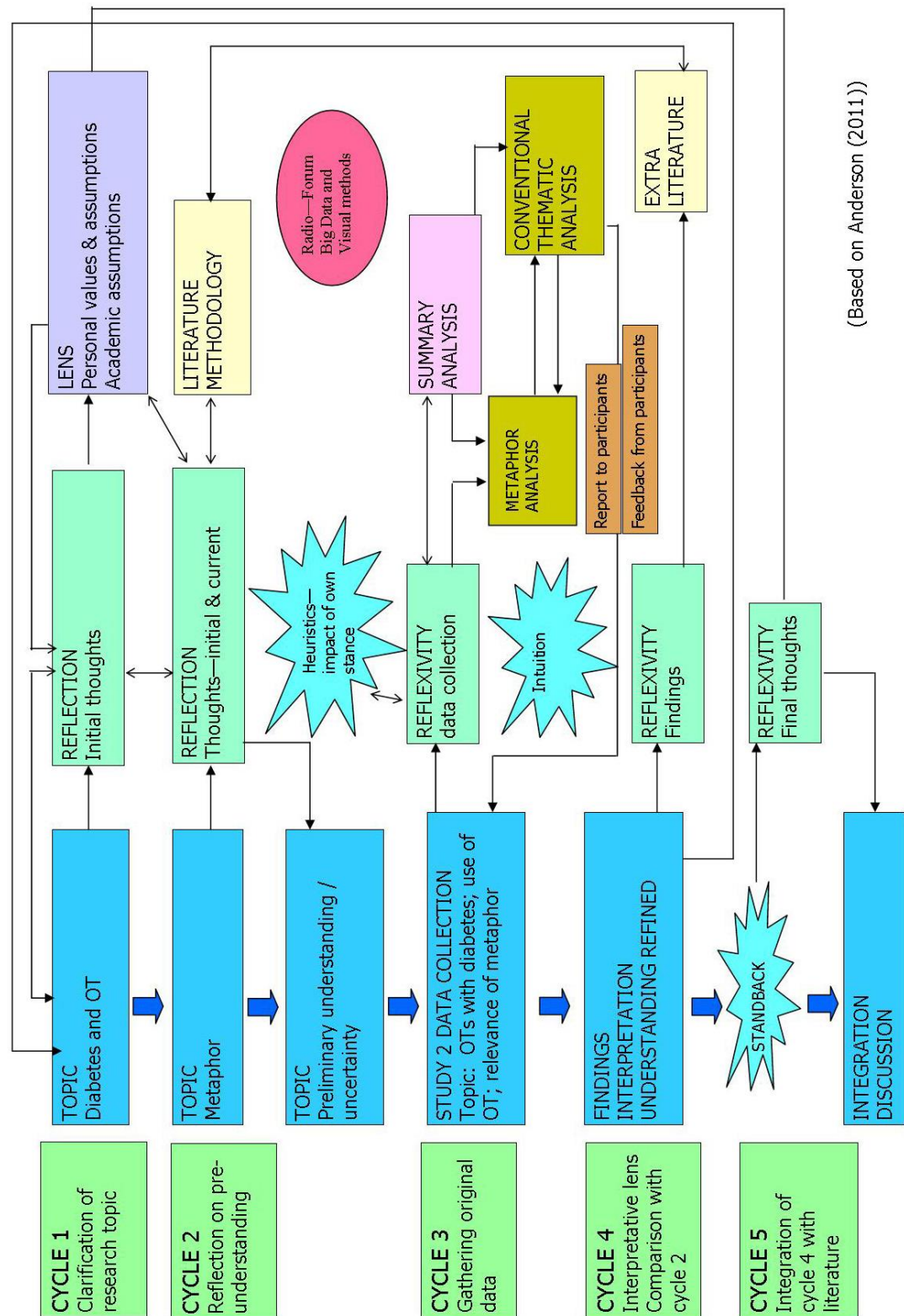
Clarifying that the aim of the study was to examine how occupational therapy could enable health and wellbeing through occupation based self management, led to the decision to explore this through the experiences of occupational therapists with diabetes. The intention was to investigate how diabetes self management was conceptualised in terms of occupational therapy and whether metaphor was useful in understanding the experience of diabetes. The use of metaphor was based on the assumption that it offered a creative way in which to

understand the richness of the diabetes experience (Broussine, 2008) and that it gave participants the opportunity to think deeply about this experience prior to the interviews (Gauntlett, 2007).

Beer (1997, p.122) suggests that it is important to allow the “*epistemological window*” through which the researcher begins to understand how the world of the participant is different and that it is the means by which the researcher can then re-examine their own understanding and assumptions. It was considered that the use of metaphor in the interviews was one way of shifting this perception and that it might also enable a more collaborative participative relationship between the researcher and participants (Beer, 1997).

### **9.7.2 Study 2 Cycle 3 Data Collection**

As in study 1, a purposive, convenience sample was sought (DePoy and Gitlin, 2011; Ritchie et al, 2003). In line with the discussion on saturation (section 9.3) it was anticipated that 5 to 10 participants would be recruited who met the study criteria of being occupational therapists who were information rich i.e. able to articulate their feelings and experiences of occupational therapy and diabetes (either type 1, type 2, gestational or pre-diabetes) and who did not have dominant coexisting health conditions which might detract from the focus of the study.



(Based on Anderson (2011))

Figure 18 Intuitive inquiry process for Study 2

Ten participants were recruited through word of mouth, via occupational therapy conference notice boards, tweets and presentations. Some snowballing occurred where people who had agreed to be interviewed identified others who fitted the selection criteria (Ritchie et al, 2003). Everyone who expressed an interest was invited to participate in the study. Diversity was maintained as participants were dissimilar in terms of type of diabetes, length of time with the condition, occupational therapy roles and geographical location (DePoy and Gitlin, 2011).

A more detailed semi-structured interview guide was produced (see Appendix 3) to meet the aims of the research questions: to understand what it meant to participants, as occupational therapists, to live with diabetes; how they had or could conceptualise using occupational therapy in their own self management; and what they saw as the role of occupational therapy generally in the management of diabetes. Prior to interview participants were asked to prepare their metaphors (Gauntlett, 2007) in the form of a picture, poem, photograph, object, or something of their own creation to encapsulate their experience of diabetes. The interview explored what metaphors participants used to describe their experience of diabetes and how metaphor might help understanding of this condition.

As in Study 1 digitally recorded interviews were conducted face to face with occupational therapists throughout England, with one interview conducted by Skype with a participant in the USA. Photographs were taken of participants' metaphors where these were presented as pictures, to complement later

analysis. While transcribing, reference was once again made to interview checklists (Legard et al, 2003; Taylor, 2005) to reflect on my own skills as an interviewer. In particular this included consideration of the impact of my own professional stance as an occupational therapist on the debate about the role of occupational therapy (Moustakas, 1990). Participants were sent copies of their transcripts for checking and to give them the opportunity to make any changes. Participants acknowledged receipt of transcript but none elected to make changes.

### **9.7.3 Study 2 Cycle 4 Interpretative Lens**

Taking experiences from study 1 of the difficulties of managing large amounts of printed transcriptions, the anonymised interview transcripts were uploaded into hermeneutic units using ATLAS ti 6.2 (Scientific Software Company, 2012) for ease of reading, coding and cross-checking (Barry, 1998; Friese, 2014). An example of the coding appears in Appendix 6. Returning to the literature on phenomenology, initial questions asked of the data were based on phenomenological “*lifeworld orientation*” questions as suggested by Finlay (2011, p.230). These included:

- What it means to be this person (self identity)
- Their sense of embodiment (embodiment)
- Where they experience their day, inside/outside (spatiality)
- How they experience their day (temporality)
- Experiences with others (relationships)
- What gives them drive, motivation, meaning (project)
- Significance of language (discourse)
- Mood / tone, expression of feelings (mood as atmosphere)

In addition “*pertinent issues*” (Finlay, 2011, p.230) were identified. A memo was written for each participant and compared across participants. This led to a

greater familiarity with the data, through a very active immersion in the transcripts, and to layers of meaning and insights that were not at first apparent. It gave an opportunity to try to understand the participants more fully, to be true to their stories, to code more widely across common experiences and to inform the themes (Finlay, 2011). Repeated readings also enabled time for thinking and reflecting. The ideas that were captured in the prepared metaphors that participants brought to the interviews (both words and pictures) were analysed separately from the main transcript data in terms of generating the metaphor, the metaphor itself, shared meanings and its usefulness to the participant.

Table 4 summarises the overall study procedures and indicates the parallel process of reflection and intuition in the right hand column. Reflection and intuition in study 2 took the form of recording thoughts and impressions in fieldwork and reflective diaries; exploring issues of creativity and analysis through reading, quilting and considering management of data sets visually (inspired by radio programmes on Considering Big Data (The Forum, 2013) and on Can Artists Make the World a Better Place (The Forum, 2014). A return was made to the methodology of phenomenology (Smith et al, 2009) to ensure that analysis was in line with key concepts. Detailed memos were written, and codes were grouped into super ordinate and sub themes reflecting the themes of living with diabetes; occupational therapy and diabetes; and conceptualisations of occupational therapy in general.

Step	What this entailed	Reflection & Intuition
1. Familiarising self with data	Transcribing interviews in full Second checking against recording Sent to participants – no changes Multiple readings	Reflective diary account about areas of significance for each interview; interview skills checked via checklists and participation in National Survey of Emotional Intelligence (percentile 97) (McKenna, 2014)
2. Initial coding	Finlay's lifeworld orientation perspective questions* Anonymised transcripts organised through use of ATLAS ti Data driven	Written consideration of pertinent issues Quilting – blocks and bags
3. Evidencing the analysis	Collating into memos – individual and collective Written detailed analysis Peer checking	Reading, making connections, significance of metaphor
4. Return to IPA	Checking analysis in line with IPA concepts	Rereading methodology Reflection on fit
5. Searching for themes	Dividing general codes into sub codes in ATLAS** Grouping codes into themes Superordinate themes and sub themes	Considering Big Data radio programme – intuitively managing data sets (The Forum, 2014) Can Artists Make the World a Better Place (The Forum, 2013)
6. Reviewing themes	Refining in terms of data set What does the theme mean? What assumptions underpin it?	Peer checking -considerations
7. Refining themes	Written detailed analysis Analytic narrative	Written reflections
8. Metaphor analysis	Separate analysis based on Cameron (see separate table)	Use of Wordle ® (2015) and pictures to represent metaphor and discourse
9. Written report	Summary of metaphors with participants' own analysis Occupational therapy themes Feedback from participants	Written reflection
10. Summary	Overall summary of study and influence on study 3	

**Table 4 Process of Analysis Study 2**

An example of the organisation of themes is given in Table 5, showing the superordinate, sub themes and interpretations of the theme of participants applying occupational therapy to their own experience of diabetes. This is further explained in Chapter 11.

APPLYING OCCUPATIONAL THERAPY (OT) TO OWN EXPERIENCE OF DIABETES		
SUPERORDINATE	SUB THEME	INTERPRETATIONS
OT ROLE	No role	diabetes did not affect occupational performance
	Uncertain role	participants described probable role but could not identify
	Potential role	hypothetical application to self management
	Specific role	clear belief in OT role to self manage
AWARENESS OF OT	Integration	assimilation of OT principles / learning on health generally
	Impact	impact of OT principles / learning on health behaviour
APPLYING OT	General principles	impact of OT values, beliefs, skills on diabetes self management
	Specific principles	specific examples of how OT applied to diabetes self management

**Table 5 Example of Grouping of Themes Study 2**

#### **9.7.4 Study 2 Metaphor Analysis**

By their very nature interviews deal with discourse (Nunkoosing, 2005) and a deeper look at how the discourse expressed participants' experiences, understanding and needs (Nunkoosing, 2005) was sought. Participants had been asked to prepare metaphors prior to interview and these were discussed with the participants during the interview to reflect their own interpretations (Gauntlett, 2007). However it also became apparent, with the focus on language, that metaphors were being used widely throughout the interviews and appeared to be significant in terms of understanding participants' experiences. Thus a metaphor analysis, based on the work of Cameron (2003), Cameron et al (2009) and Cameron and Maslen (2010) was undertaken. The process of this analysis is summarised in Table 6.



Step	What this entailed
1. Identifying metaphors	Operational definition of metaphor Check against definitions and <i>Thesaurus of Traditional English Metaphors</i> 2 <sup>nd</sup> Ed (Wilkinson, 2002)
2. Search through data	Identify metaphor, note participant, paragraph number
3. Apply vehicle group	Common source domains Adjusting vehicle groups where more than one could apply
4. Look for patterns / clusters of metaphor	Identify numbers
5. Metaphor synthesis	Range of metaphors and what connects them

**Table 6 Process of Metaphor Analysis Study 2**

The first step of metaphor analysis is to identify an operational definition of metaphors for consistency. Cameron and Maslen (2010, p.102) concede that there is no watertight definition and that it is about *“identifying words or phrases that can be justified as somehow anomalous, incongruent or ‘alien’ in the on-going discourse”*. By this they mean words or phrases that have one meaning in the context but also another different meaning. The definition by Lakoff and Johnson (1980, p.5) of metaphor as *“understanding and experiencing one kind of thing through another”* is most commonly used. Conceptual metaphors consist of *“two conceptual domains in which one domain is understood in terms of another”* (Kosvecses, 2002, p.4). The two domains are known as the target and the source. Kosvecses (2002, pp.16-20) lists examples of source domains such as movement and direction, war, buildings, food, plants, containers, forces. Those of movement/direction might include describing the target, for example diabetes self management, in terms of *step by step*, or *following a particular path*.

All metaphors across all participants were identified using the definitions above and with reference to a thesaurus of metaphors (Wilkinson, 2002). An example of

a page from the thesaurus (On the Road), adapted from a screen shot is given below in Box 2. Some words originally considered metaphors were removed eg the word 'challenge' was deleted, after consultation with the thesaurus, as there are metaphors which describe challenge. Similarly the word 'control' was removed as there are metaphors to describe being in or out of control. However, due to the prevalence of the word control in the discourse, this was then separately thematically analysed (Braun and Clarke, 2006) within the context of the narrative.

Prepositions are seen as metaphors (Cameron, 2003) but these were only chosen when they referred to an object or place being used metaphorically eg 'I put things *in* boxes *in* my head'; 'it went *over* my head' (this is metaphorical in the sense that one cannot actually put items in a box in a head, or an item does not actually move over someone's head). In addition prepositions such as 'up' and 'down' appear regularly in terms of blood sugar 'escalating' or 'dropping'. These are used metaphorically to indicate movement/direction in an attempt to find some sort of balance/normality (Cameron and Maslen, 2010).

someone on their way for a short distance only.
<b>conducive/conduct</b> [<Lat <i>con-ducere</i> =lead together with, accompany]
<b>fellow-traveller</b> [1936] One in sympathy with, but not a member of, a political party.
<b>down the road</b> [Amer] In the future.
<b>go down that road</b> Commit yourself to a course you are likely to regret.
<b>not get very far along the road</b> Make little progress.
<b>half-way down the pike</b> [=turnpike=road—Amer] Only partly developed or realised, incomplete.
<b>middle-of-the-road man</b> [1894] One who avoids the extremes, a moderate.
<b>arrive at/reach—a mental decision, conclusion; an agreement, compromise</b> (The pure meanings of coming right up to a distance or destination, and of grasping with the hand, have been extended into the mental and social spheres.)
<b>reach the end of the road/line</b> [=railway-line—Amer] Arrive at a point beyond which you can make no further progress and further effort is futile.
<b>you can't get there from here</b> [Amer] It is an insoluble problem.
<b>take the blue road</b> [Wil] Go to live or work in the town.
<b>take the white road</b> [Wil] Go to live or work in the country.
<b>there will be rubs in the smoothest road</b> Nothing is ever perfect.
<b>a bump in the road</b> Minor difficulty, not enough to affect the issue or the progress.
<b>a lean dog for a hard road</b> [1917] (because carrying no surplus weight) In hard times the fewer responsibilities and possessions the better.
<b>'it's a hobbly/knobby [lumpy—Cum] road!'</b> as the man said when he fell over a cow in the dark [nEng]
<b>keep in the right path</b> Stick to your principles, do not be diverted from what you know to be right.
<b>our paths crossed</b> We chanced to meet.
<b>in/within sight of...</b> Near to achieving, almost arrived at your objective.
<b>see your way (clear) to...</b> [1774] Bring yourself to; be able and inclined to do something.
<b>love will find a way</b>
<b>come my way</b> Arrive fortuitously; receive gratuitously. The opportunity soon came my way to...'
<b>go a long way towards</b> Make a generous contribution to; do much towards achieving—agreement, a satisfactory solution etc.
<b>go all the way/the whole way</b> Carry lovemaking through to its conclusion.

Box 2 Example page from Wilkinson (2002, p398) of metaphors related to being On the Road.

Once classified the metaphors were then applied to conceptual vehicle groupings (Cameron and Maslen, 2010). An example is given in Table 7 and the complete list features in Chapter 11.

Where metaphors could apply in more than one grouping (eg step \*\*, track\*\* and running\*\* in Table 7) a decision was made as to its most relevant grouping in terms of the context of the metaphor. In order not to have too many vehicle groupings, which would make the data unwieldy, vehicle groupings were combined, such as journey with movement/direction.

VEHICLE GROUPING	METAPHORS
FORCES	crack, dominating, shove(d), bump, shock(ed), pressure, builds up, hard, stress, fluid, hit, push (ed), pushing, empower, reign in, turbulent, chaos, break, breaking, break down, storm, positive, power, slap, powerful, drag, heavy, energies, kick, nudge, strike, lean on, hot, knock back, pull, stretch, budge, struck, break, rub off, crashing, upheaval, shock, sucks, pushing, heavily
GAMES/SPORT	kicked, throw, target, game, waterslide, yoyo, catch, run, runs, running**, track**, tackle, back foot, spot, rules, bet, pitch, trigger, clue, threw, deal, ball game, chance, cue, net, racing, jump, rules
JOURNEY	step**, bit by bit, path, pathway, track**, journey, course, end, route, on board
MOVEMENT/ DIRECTION	moving, went, fall, fall out, fall apart, down, pans out, escalating up, high, higher, over, up, up to, low, scale, drop, above, depth, off, yoyo, near, heading, dropped, peak, all over, distance, get to, direction, from, downhill, ran, running**, run, under, step**, back, knock back, send, set back, laidback, trotted, shuffle, driven, knock back, there, pace, fall apart, slip, slope, spike, forward, uphill, coming at, standstill, creep, navigate, off, flip over, flip into

**Table 7 Sample of Metaphors and their initial vehicle groupings Study 2**

These metaphors of everyday language were then analysed according to the context in which they were used: diabetes diagnosis; diabetes self care (participants' own management); diabetes general management; life experience; lifestyle; occupational therapy generally; occupational therapy work role. Analysis included the range of vehicle groups, how often the metaphors occurred and how many participants used them.

A way of visually understanding the metaphor data was sought to get a feel for its significance. The data were entered into Wordle<sup>®</sup> (2015) to create word clouds to indicate the relative values of the metaphors used in general (see p.226). An attempt was also made to visually represent the particular movement/direction aspect of trying to balance out or get blood sugars under control.

As in Study 1, the data analysis was not a linear process, as indicated in Figure 18, and many returns were made to the data with reflection, evaluating, rereading literature and applying creativity all included.

A report detailing a summary of the findings was sent to all participants for review and comment. Although on-going participation in the study was entirely voluntary, four of the ten participants responded and indicated that they felt that their views had been represented and expressed interest at both other metaphors produced and the language used.

#### **9.7.5 Study 2 Cycle 5 Integration**

Integration of cycle 4 with the literature appears in the discussion in Chapter 11. On the basis of the findings of this study the original intention was to contact occupational therapists working in diabetes care to ascertain the ways in which what had been discovered about the lived experience and what had been learned from occupational therapists with diabetes compared with their practice. A questionnaire was designed and piloted on two occupational therapists in the UK, who had knowledge of diabetes but did not work specifically with people with diabetes. An initial request for participants was sent to 3185 occupational therapists through the International Model of Human Occupation listserv (<http://www.cade.uic.edu/moho/resources/listserv.aspx> (2013)). This resulted in just one response from an occupational therapist in South East Australia who commented that the current diabetes guidelines in her area did not include occupational therapy. A further opportunity arose for opportunistic sampling (Ritchie et al, 2003) at the 16<sup>th</sup> International Congress of the World Federation of

Occupational Therapists, attended by 6400 delegates from 72 countries (Bressler, 2015). Recruitment was attempted at the Congress through notice board messages, tweets, leaflets, poster and paper presentation and general conversation. Anecdotal discussion indicated that no occupational therapists were working directly with people with diabetes and no participants met the criteria for this study. This could be seen as indicating that there is no role for occupational therapy and this is discussed further in Chapter 13 within the theoretical discussion and where the limitations of the study are considered.

Study 3 was then redesigned, in the light of the Study 2 findings, to recruit members of the general public with diabetes to further ascertain the value of metaphor to understand experiences of diabetes and to explore those experiences in relation to the potential role of occupational therapy.

## **9.8 Study 3 Diabetes in Relation to the Potential Occupational Therapy Role**

Figure 19 summarises the intuitive inquiry process for Study 3. As with Study 1 and 2 the cycles of the process will be discussed in turn, highlighting both the procedure and the opportunity for reflection on the research process.

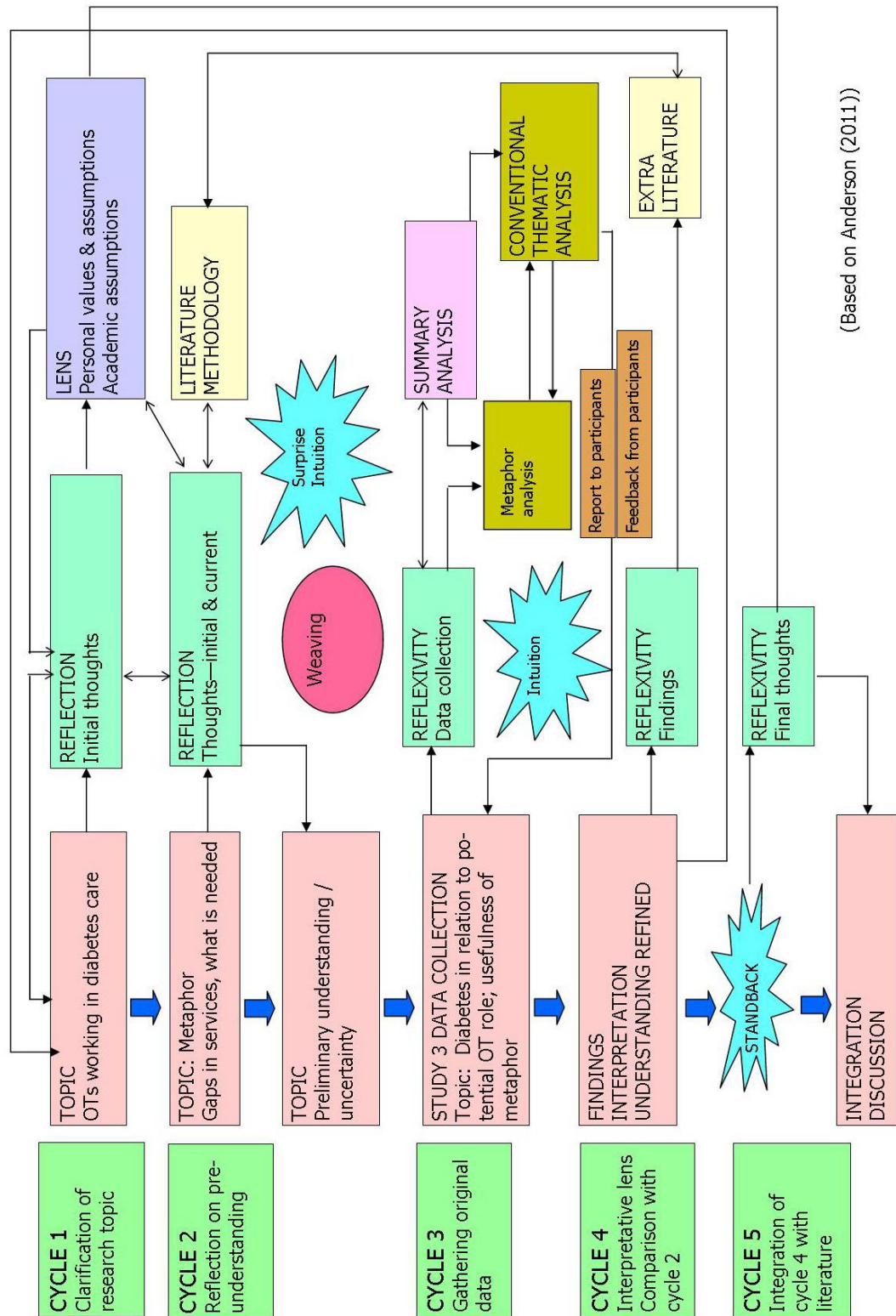
### **9.8.1 Study 3 Cycle 1 and 2 Clarification of the Research Topic**

As discussed above in Cycle 5 of Study 2, the course of the research study altered to examine the potential role of occupational therapy in the light of the findings

of that study. A review of the literature, particularly on metaphor, indicated that it was an effective way to explore diabetes (Stuckey, 2009; Stuckey and Tisdell, 2010) and thus it was resolved to continue with this method. Additionally it was decided that a more specific focus on what people thought would help their diabetes healthcare experiences would be useful to ascertain whether this could be matched by the values, beliefs and skills of occupational therapy practice. The interview schedule (see Appendix 3) was redesigned to reflect these changes.

### **9.8.2 Study 3 Cycle 3 Data Collection**

As in Studies 1 and 2, and in line with interpretative phenomenological analysis (IPA), a purposive, convenience sample of people was sought (Smith et al, 2009). In line with the discussion on saturation (section 9.3 above) it was anticipated that 5 to 10 participants would be recruited who met the study criteria of being adults over the age of 18 who were information rich i.e. able to articulate their feelings and experiences of diabetes (type 1, type 2, gestational or pre-diabetes) and who did not have dominant coexisting health conditions which might detract from the focus of the study. Participation was entirely voluntary. Participants were recruited initially by word of mouth.



(Based on Anderson (2011))

Figure 19 Intuitive inquiry process Study 3



Once again I talked about the study widely with colleagues and acquaintances and received approaches from people who believed they knew others who might wish to take part in the study. Potential participants were approached by these third parties to enquire whether they wished to participate. Where this was agreed, I then followed up the invitation by telephone or email to discuss the study further and to ascertain that they met the study criteria. In this way five participants were recruited from the North West and South West of England with varying lengths of time since diabetes diagnosis. As discussed in the section on ethical considerations, participants were sent information sheets and informed consent was gained prior to each interview. As in Study 2 participants were asked to prepare their metaphor for diabetes (Gauntlett, 2007) prior to interview.

As in Study 1 and Study 2 digitally recorded semi-structured interviews were conducted face to face with participants (Todd, 2006). All participants described their metaphors verbally without pictures and thus no photographs were taken. Participants were sent copies of their transcripts for checking and to give them the opportunity to make any changes (Nunkoosing, 2005). One participant made extensive edits to her transcript, stating that she was concerned at how “*garrulous*” she sounded. One other participant clarified some statements in her transcript that she felt were not clear.

### **9.8.3 Study 3 Cycle 4 Interpretative Lens**

The anonymised interview transcripts were uploaded into hermeneutic units using ATLAS ti 6.2 (Scientific Software Company, 2012) for ease of reading, coding and cross-checking (Barry, 1998; Friese, 2014). As these had been useful in Study 2, the phenomenological lifeworld orientation questions were initially asked of the data and pertinent issues were identified (Finlay, 2011). A memo was written for each participant and compared across participants (Smith et al, 2009). Repeated readings enabled time for thinking and reflecting. The ideas that were captured in the prepared metaphors that participants brought to the interviews were analysed separately from the main transcript data in terms of generating the metaphor, the metaphor itself, shared meanings and its usefulness to the participant. Table 8 summarises the overall study procedures and indicates the parallel process of reflection and intuition in the right hand column.

Preliminary analysis of the data revealed that metaphors used in the general discourse were similar to those used in Study 2 and thus it was not felt that the level of detail of metaphor analysis (Cameron, 2003; Cameron and Maslen, 2010) employed in Study 2 was essential.

Detailed memos of the interview data in general were written, and codes were grouped into super ordinate and sub themes reflecting the themes of living with diabetes; gaps experienced in diabetes healthcare service and impact on health and wellbeing; value of metaphor to conceptualise diabetes experiences; potential role of occupational therapy to meet needs. Intuition and reflection in

this study took the form of recording thoughts and impressions in fieldwork and reflective diary; exploring issues of creativity and analysis through weaving and through studying a massive on-line open course (MOOC) on medicine and the arts (University of Cape Town,2015).

Like Studies 1 and 2, the data analysis was not a linear process, as indicated in Figure 19, and many returns were made to the data with reflection, evaluating, rereading literature and applying creativity all included.

A report detailing a summary of the findings was sent to all participants for review and comment (Gauntlett, 2007). Although ongoing participation in the study was voluntary, four of the five participants responded. They indicated that they felt that their views had been represented and expressed interest at the other metaphors produced and at the shared experiences with other participants.

Step	What this entailed	Intuition and reflection
1. Familiarising self with data	Transcribing interviews in full Second checking against recording Sent to participants – incorporating changes Multiple readings	Reflective diary account about areas of significance for each interview
2. Initial coding	Finlay's lifeworld orientation perspective questions Anonymised transcripts organised through use of ATLAS ti Data driven	Written consideration of pertinent issues
3. Evidencing the analysis	Collating into memos – individual and collective Written detailed analysis	Reading, making connections
4. Searching for themes	Dividing general codes into sub codes in ATLAS Grouping codes into themes Superordinate themes and sub themes	MOOC – medical humanities & interdisciplinarity (University of Cape Town, 2015)
5. Reviewing themes	Refining in terms of data set What does the theme mean? What assumptions underpin it?	Looking for holism – art work – weaving Interpretations?
6. Refining themes	Written detailed analysis Analytic narrative	Reflective diary on themes and feedback
7. Written report	Summary of metaphors with participants' own analysis Feedback from participants	
8. Summary	Overall summary of study	

**Table 8 Process of analysis Study 3**

#### **9.8.4 Study 3 Cycle 5 Integration**

Findings for Study 3 are reported in Chapter 12 and findings from all three studies are considered together in the theoretical discussion of Chapter 13. Consideration of the links between the three studies suggested that a return to the Study 1 data to look for metaphors in the general discourse would be useful to see how this compared to Study 2 and 3. The general process of metaphor analysis (Cameron and Maslen, 2010) as described in Study 2 (see Table 6) was employed.

Throughout the three studies, it was important for me to explore and analyse the data using phenomenological and thematic analysis (Braun and Clarke, 2006; Finlay, 2011; Smith et al, 2009). As part of the rigour of the research study an attempt was made to consciously bracket out my professional understanding as an occupational therapist within the analysis, so as to avoid fitting the data to the theory (Dowling, 2006; Finlay, 2002a). Although it has been argued that it is almost impossible to unknow what is already known, and accepting that one's subjective experiences will knowingly or unknowingly influence the study (Bishop and Shepherd, 2011; Bradbury-Jones, 2007; Cutcliffe, 2003; Finlay, 2002b), this was a deliberate choice so as not to miss the nuances of the data by potentially narrowing the focus into a preconceived occupational therapy framework (Nayar and Stanley, 2015) at this stage. Instead this was about opening up the data to wider interpretations using Finlay's (2009) rich descriptions and by questioning my own interpretations.

Drawing all the findings together of the 22 participants with some confidence that this had been achieved, the findings as a whole were then considered in the context of an occupational therapy theoretical framework, that of the Model of Human Occupation (MOHO) (Kielhofner, 2008) in order to explore the understanding of diabetes self management from an occupational therapy perspective. MOHO was first introduced in the occupational therapy section of the literature review (see p.47). As described, MOHO concepts address motivation for occupation, routine patterning of occupational behaviour, nature

of skilled performance, and the influence of environment on occupation (Forsyth and Kielhofner, 2003). Chapter 13 discusses a model for the occupation of diabetes self management based on the MOHO (Kielhofner, 2008) and considers a framework for occupational therapy intervention in diabetes self-management.

## **9.9 Rigour, Credibility and Trustworthiness**

There is much debate but little agreement on how to judge the quality of qualitative research due to different methodologies, theoretical and value assumptions, and philosophical issues concerning claims to knowledge (Finlay, 2006; Hammersley, 2008). Due to the pluralistic nature of qualitative research, it cannot all be assessed with the same criteria (Caelli et al, 2003; Finlay, 2006; Hammell, 2002; Krefting, 1991). Thus the criteria need to be compatible with the particular aims, methodology and epistemology of the research (Finlay, 2006a; Hammell, 2002).

A number of models and checklists have been developed (see Hammell, 2002; Spencer et al, 2003; Tracy, 2010; Whitemore et al, 2001; Yardley, 2000) to assess the rigour, credibility and trustworthiness of qualitative research. These include examining such terms as truth value, applicability, consistency, and neutrality (Krefting, 1991 based on Lincoln and Guba, 1985). Other areas for examination include integrity, criticality, and authenticity (Whitemore et al, 2001). Finlay (2011) suggests examining rigour, relevance, resonance and reflexivity while Yardley (2000) advises analysing sensitivity to context, commitment and rigour, transparency and coherence, plus impact and importance. Hammell (2002)

argues the need to consider authenticity and plausibility, while Caelli et al (2003) recommend addressing the theoretical positioning of the researcher, and the congruence between methodology and methods.

Within intuitive inquiry and phenomenology, the aim is to describe and interpret the experiences of the participants (Anderson, 2011; Smith et al, 2009) but while the findings and discussion may reflect this, there is still a need to critically evaluate the research processes to establish the validity of those findings (Whittemore et al, 2001). To this end, and with regard to the models and checklists described above, the criteria for assessment of quality for this study are based on the design and the findings (Spencer et al, 2003). These include ethics, defence of the design, the sample, data collection, and analysis. Ethical issues have previously been discussed in section 9.5 and the other criteria are here examined in turn.

### **9.9.1 Defence of Design**

Criticism of a pluralistic methodology, or bricolage, is that it can be seen as slurring (Baker et al, 1992) or sloppy (Hammersley, 2008; Morse, 1991) but the opposing view is that studying the topic from a number of perspectives can be a strength (Whittemore et al, 2001). Hammell (2002) suggests that if a specific design approach has been stated, there should be evidence that the guidelines have been followed. Whittemore et al (2001, p.526) also suggest that adherence to method *“is not an assurance of validity”* and that confining oneself rigidly to a specific method can potentially reduce the sensitivity to nuances of meaning (Whittemore et al, 2001).

Whittemore et al (2001) see a tension between rigour and creativity, and that adhering to a systematic approach to give credibility could be at the expense of creativity. Finlay (2006, p.322) argues that within qualitative research a creative dimension should be applied, to capture the richness of the lived experience and to reflect the “*potential power*” of the research. Credibility is seen as the extent to which the findings reflect the experience of the participants in a believable way and that the interpretations by the researcher are trustworthy (Whittemore et al, 2001). Authenticity is the way in which the research accurately portrays awareness of all the different voices of the participants (Whittemore et al, 2001).

To address the defence of the study design and these issues of credibility and authenticity, there is evidence documented in the study design that guidelines for phenomenological research have been followed and also that the researcher has been open to the creative dimension in order to intuitively portray the experiences of the participants. The following chapters 10, 11 and 12 on Findings and Discussion aim to convey the voices of the participants accurately and plausibly.

### ***9.9.2 Further Consideration of Data Analysis within this Study***

It is argued that analysis and the knowledge gained from this will always be affected by pre-existing values and ideas (Seale, 1999). As previously discussed in Section 8.7 (p.126), one way of exploring the impact of these values and ideas is through reflexivity but Mauthner and Doucet (1998) suggest that little attention has been given to this in data analysis. A deliberate attempt was made in this



study to explicitly show the impact of reflection and intuition on the analysis, as shown in Tables 3, 4 and 8 above. The continuum between reflection and reflexivity (Finlay, 2002a) was introduced in section 9.6 in which reflection was seen as a more distant thinking about the study, and reflexivity as more of a self awareness in the moment of the research. The reflective journal took the form, as suggested by Krefting (1991) of a daily schedule; methods log / decision trail; and reflections – thoughts, feelings, ideas, questions. In this way reflexivity was used as a way of being honest in research (Bishop and Shepherd, 2011), to explore the tensions in the analysis and to maintain integrity (Whittemore et al, 2001). Bracketing is seen as the means by which the researcher's preconceptions and their impact on the research can be mitigated (Larkin et al, 2006; Tufford and Newman, 2010). This topic was first introduced in Section 8.7 (p.126) and developed in Section 9.8 Study 3 Cycle 5 Integration (p.172). While it is acknowledged that it is impossible to completely bracket out one's understanding and prior knowledge (Snelgrove, 2014), attempts were made as described earlier on to be aware of my own prejudices and assumptions in the research design, interviews and the data analysis, through being reflexive and self critical (Allen-Collinson, 2011). However it is also conceded that my own connection with the research topic could be seen as a strength in alerting me to identify issues or themes in the data (Ahern, 1999; Drew, 2004).

Two further methods to enhance the analysis were employed. The first was peer checking. Krefting (1991, p.219) refers to this as discussion of the analysis with an 'impartial' colleague with experience in qualitative methodology. One of the

interview transcripts from Study 2 was sent to a colleague from a different discipline for sharing of codes and theme categories. This allowed for deeper reflection on the analysis and consideration of areas of importance. The other was member checking. Krefting (1991) argues that findings can be viewed as truthful if the people who share that experience recognise them as accurate descriptions. To that end a report of the findings of each study was compiled and sent to participants for voluntary feedback to ensure that their viewpoints were accurately represented. Mays and Pope (2000) argue that this check of credibility is limited due to different roles in the research process and that general accounts will differ from the individual participant's one. They argue that it is better to conceive this as the process of error reduction. Although on-going participation was entirely voluntary, three out of seven participants responded to the report in Study 1, four out of ten in Study 2, and four out of five in Study 3. While it is accepted that not all participants responded to member checking, those that did indicated that they felt that their views had been represented, which denotes at least a level of accuracy.

## **9.10 Summary**

This chapter has described the study design in detail with consideration given to the ethics, credibility and trustworthiness of the research. The following Chapters 10, 11 and 12 discuss the findings of the three separate studies and these are then considered as a whole in Chapter 13. The decision flow and time line diagram (Figure 20 below) summarises the decisions made in the study and is colour co-ordinated in keeping with the stages described above. The boxes on

the right (in light blue) summarise the initial and on-going influences which impact on the study actions depicted on the left. The yellow, blue and pink boxes on the left represent studies 1, 2 and 3 (as in Figure 16, p.137). The lilac boxes on the left represent potential actions. The final two green boxes on the left represent the potential theoretical framework at the centre of the pyramid in Figure 16. The reflection which follows considers the impact of myself on the interviews.

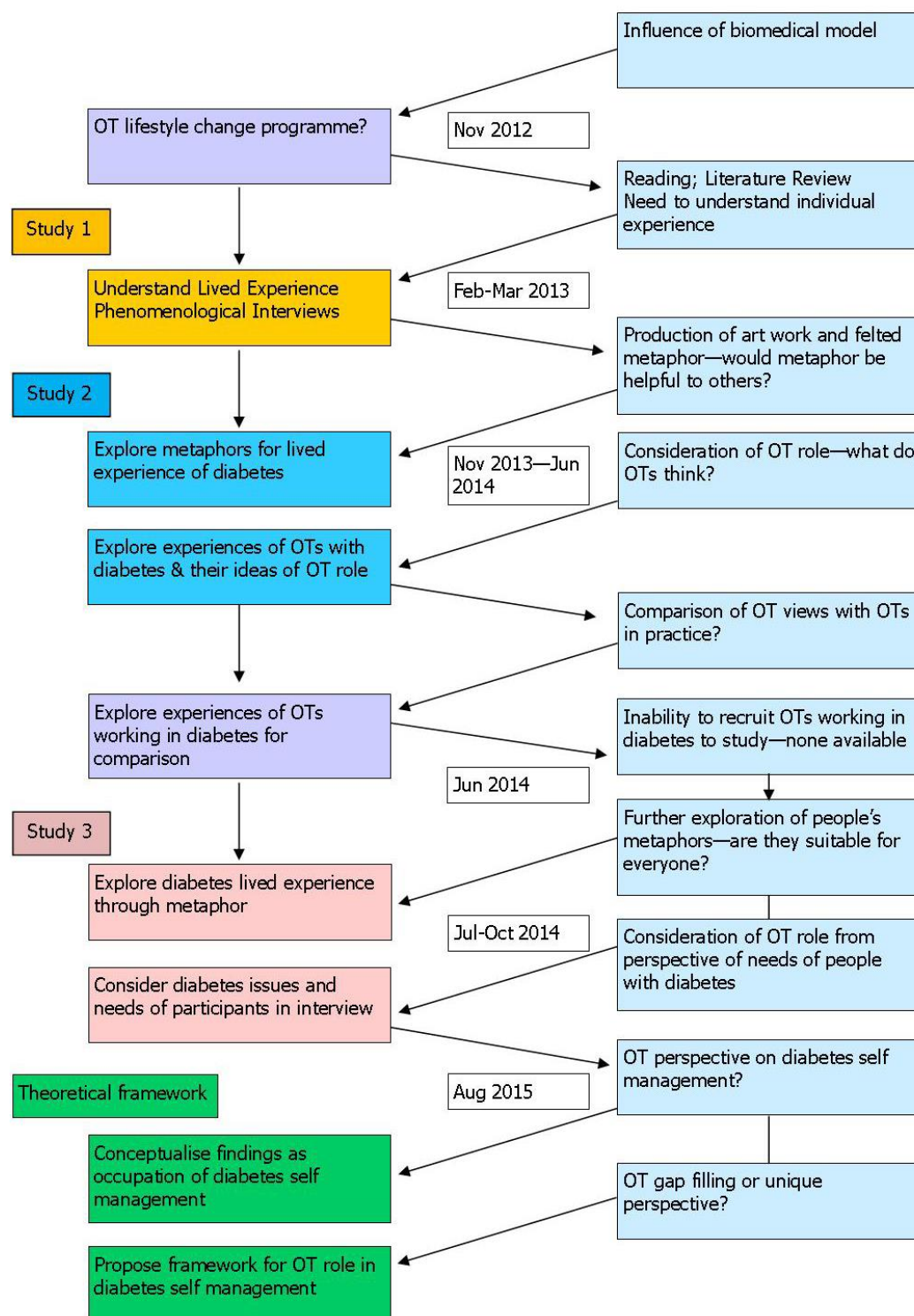


Figure 20 Decision flow diagram with time line

### ***Reflection on interviews:***

*In my readings on interview, I found that writers are clear that the aim is to explore the things that are pertinent to participants rather than discussing things that may reinforce the interviewer's preconceptions (see particularly Taylor, 2005, p40). Taylor suggests also looking at how reactions to particular participants might have influenced the interview. Writing about frustrating experiences can be cathartic and reflecting helps to find ways of improving the interview (p44). In relation to participant 2 I got the feeling towards the end that he was neatly side tracking all my questions about his thoughts and feelings on diabetes so it turned into a general discussion about the conduct of GPs - was this feeding into my preconceptions? I was aware that I was expressing opinions (not really interviewing as such) but at the time it seemed the only way to engage him. Is this acceptable, was it allowing him to set the agenda or was I influencing this? Was it giving him respect to engage in the discussion this way? And then I stopped the interview. I wondered about how it is different from gathering information as a practitioner and whether it matters how directive one is? Sometimes there are times when you feel that you let the topic disappear without being examined more fully so go back to it. Is this wrong? Lots to think about and examine in relation to my interviews. (March 2013)*



**Figure 21 Mining the Data**

*I applied gel medium to the paper, cut out mining tools from sheets of foam and applied them to the gel to create a pattern of tools on the cave walls (like ammonites) which I then coloured with acrylic paints. I painted the large crystal in the middle with copper, silver and gold paint, marking it with pen tops and then made other mining marks in the cave walls with the end of a sellotape dispenser. I created the floor of the cave by using a textured roller on gesso. Finally I glued on the foam mining tools.*

*Following on from Immersion, I felt I needed to go back to the 'coal face' for more mining of the data (reading, rereading, analysing, thinking) for the rough diamonds or other precious stones in the data. The crystal cave is an attempt to reflect the need I felt to keep going, not be satisfied with a cursory surface view and to 'dig deep' for what the data were telling me.*

## **10.0 Study 1 Findings and Discussion**

### **10.1 Chapter Outline**

This chapter describes the findings of Study 1 The lived experience of diabetes. Discussion of those findings follows. As indicated in the Study Design Chapter, the findings are colour coded to differentiate between the three studies. Tables in this Study 1 are in yellow. A theoretical consideration of the findings all three studies and the links between them will be examined in Chapter 13. The findings for this study have been published (Youngson et al, 2015) and presented at national and international occupational therapy conferences (see Public Output, p.vi).

### **10.2 Study 1 The Lived Experience of Diabetes**

This first study sought to understand the personal issues and reality of living with diabetes from an occupational perspective. This section describes the participants and introduces the themes of the lived experience.

#### **10.2.1 Study 1 Participants**

Seven people with a diagnosis of type 1, type 2 or pre-diabetes were recruited to the study. Table 9 shows the demographic details of the participants. All participants were employed, with the exception of Alan and Anna who had both retired, and all commented that they had strong family support, either from partners or from parents. They discussed their changing attitudes, attempts to self manage and their thoughts on living with diabetes.

Simon and Rosemary, both with type 1, had a long experience of the condition. Rosemary reported that she had given birth to large babies and suspected that her diabetes had started during pregnancy. Simon's had been diagnosed when he was aged 9 and he had had to make adjustments as he grew up to take over management from his parents.

Participants' Pseudonym	Age	Type of diabetes	Time since diagnosis
Rosemary	50	Type 1 diabetes	19 years
Simon	23	Type 1 diabetes	14 years
Alan	64	Type 2 diabetes	4 years
Anna	64	Type 2 diabetes	12 years
Terry	41	Type 2 diabetes	6 weeks
Albert	51	Pre-diabetes	8 months
Rachel	54	Pre-diabetes	5 years

**Table 9 Demographics of Participants Study 1**

The participants with type 2 had a variety of experiences and length of time with the condition. Alan's began following surgery and he felt that on the whole his condition was very stable and manageable. Anna's story was about turning around her management of diabetes. After a number of years of ignoring her symptoms she had decided to take control and reported she had lost 13 stones in 12 months. Terry had been recently diagnosed and was able to give a perspective on the early part of his diabetes journey. Although he had noticed warning signs and was not surprised at the diagnosis, he described his struggle and shock at having to confront the lifestyle changes.

Albert and Rachel had been diagnosed with pre-diabetes. Like Terry, Albert was at the start of his journey, although was suspicious about being given the 'label'



of pre-diabetes. Rachel's diagnosis had occurred 5 years previously and she described the difficulties of trying to prevent the development of type 2 diabetes without support of the health services.

### **10.2.2 Study 1 The Themes of Living with Diabetes**

As previously described in Chapter 9, Study Design, the reflexive and creative analysis of all participants' experience of diabetes produced rich data about their shared understanding. The felt metaphor of charting a course of health and wellbeing through the choppy sea of life (see Figure 22 below) is first explained, as described to the participants in the interim report:

*In this metaphor the boat is the person with diabetes or pre-diabetes charting a course of health and wellbeing, but inevitably is sometimes blown off route by the wind and waves. The waves are lifestyle issues – family problems, jobs, anything else that temporarily impacts on life and steers you away from the normal course. Illness symptoms also impact on the boat and the boat can deteriorate as a result of this but still sails on while the waves are being dealt with and until things can go back on course. Sometimes there are calm seas where things are under control and going well but sometimes the waves impact on the balance that everyone is trying to find: living with a condition but also wanting to live a 'normal' life..... In the sea there is flotsam and jetsam – some of this is helpful but some can stall and weigh you down. Some of you found inspiration that helped you change course – in the metaphor of the seascape this could be an amazing sky, birds, whales or dolphins. Lighthouses can show the way and also indicate danger. The sea cannot be mastered but a course can be steered through it. Steering the boat is trying different aspects, diets, lifestyle changes – sometimes making progress, sometimes not..... Sometimes the sea will be flat calm but usually there is a roll and resources are required for dealing with it. In terms of intervention, the healthcare providers are represented by the boat repairers' yards – mending and advising, strengthening the boat, being a port in a storm. Advice and education could be around understanding the sea (the wind and the waves), learning how to sail the boat, to get on track, try new courses through the sea, tackle the waves in a different way, or to keep the boat mended and seaworthy.*



**Figure 22 Felted Metaphor: Charting a course of health and wellbeing through a choppy sea**

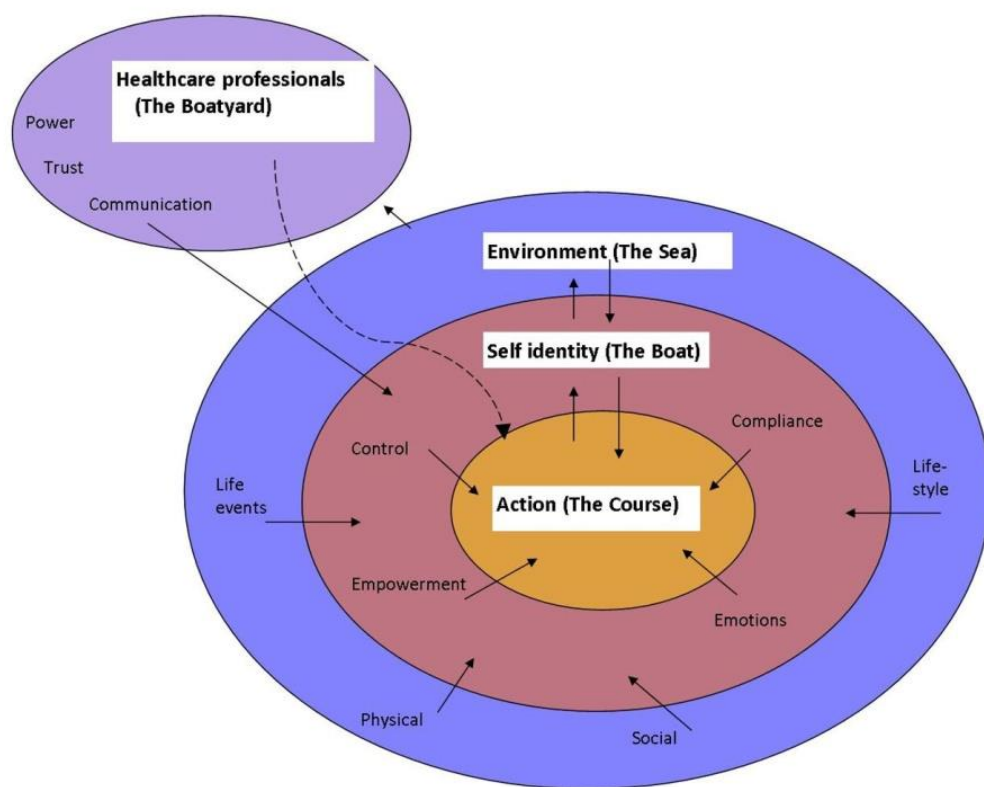
The key themes from the data, in relation to the sea metaphor, are summarised more traditionally in Table 10 below.

Major theme	Sub themes	Representation in metaphor
Impact of Environment	Physical environment Social environment Lifestyle Life Events	The Sea
Self Identity	Control Balance Compliance Empowerment Emotions	The Boat
Individual Action	Information gathering Change Self management	The Course
Relationships with healthcare providers	Power Trust Communication	The Boatyard (outside the picture boundary)

**Table 10 Key Themes Study 1**

Figure 23 shows how the sea metaphor relates to these key themes and how they interact to affect participants' ability to manage their diabetes. This diagram conveys how the environment and participants' identity in particular impacted on

their individual action towards managing diabetes, which in turn had consequences on their identity and environment. Relationships with healthcare providers are shown as separate, denoting the issues that arose in terms of power, trust and communication. These major themes, as in Figure 23 will each be reported and quotes are included throughout to give voice to the participants and to evidence representation of the findings. Due to the shared nature of the experiences the term 'diabetes' is used regardless of the type of diabetes of the participant.



**Figure 23** Interface between the findings and the visual metaphor

### 10.2.3 Study 1 Impact of Environment

Many aspects of the environment, symbolised by the sea in the metaphor, had the impact of 'blowing people off course' or making it difficult to find a way forward to managing their diabetes. As shown in Table 10 and Figure 23, this included the physical and social environment as well as wider aspects of lifestyle and life events. Attempting to balance many aspects of life, led to stress, while for those in employment, sedentary or chaotic work life affected meals, medication and testing in particular:

*I think I'm so busy that for a lot of the time I do forget to have injections, meal times are completely erratic during the day, I very seldom have anything to eat during the day, I go off to work and that's that. (Rosemary)*

*Where now I have to think 'well if I'm going to be out for dinner I need to take a sandwich or I need to buy a sandwich or I need to look at...' but if you go into areas that you don't know, you're not going to know if anybody, where's open. So you need to take something with you just in case places aren't open. (Terry)*

*No, it's difficult because I spend so much time away in hotels. I'm away 3 nights next week in hotels. So I'll probably do Tuesday on the diet and then I'll probably do Thursday. (Albert)*

*If you have a lifestyle that has some stresses in it, you choose ways to deal with that, don't you. Like, if I gave up my job I don't think I would eat anything like the amount of goodies I do now. (Rachel)*

Major life events such as ill health, redundancy or difficult personal circumstances had consequences as these were given precedence over managing diabetes:

*It was a horrible time, it was a really, there was lots and lots of things happening that were really horrible and I think I just, I didn't bother about myself at all, you know..... I came so far down the list that I just wasn't bothering. (Anna)*

*Problems with the business and so on had become such hard work for the whole family really, for so long, and the stress and coping, and my husband's depression and stress and everything had just been another focus. (Rosemary)*

Although all participants felt that they had support from partners or family, friends could also be a hindrance to management, especially in terms of temptation. Terry, newly diagnosed, explained:

*It's quite hard really, I find it quite difficult. Especially when everybody in work are eating sweets and cake and biscuits and putting them in front of your face going "Mmmmmm, look at this cream cake" and they know I'd be the first one in cream cake box or sweet box or whatever. (Terry)*

The physical environment, such as steep hills or proximity to gyms or pools influenced participants' routines and motivation to exercise as part of their diabetes management:

*We are quite out of the way in the normal sense of things. So it is so much easier just to get in the car. (Alan)*

*When I was at Uni and living on campus I got like a year's pass to the swimming pool and went kind of nearly every day for most of the time I was there and that was, I think that really helps because I got that into a kind of routine and ..... that was when I got my best HbA<sub>1c</sub>. (Simon)*

The need to be aware of new diabetes routines, and the major impact they could have on lifestyle is best summed up by Terry:

*Cause I used to be more like 'ah well, if I'm diabetic, I'm diabetic, I'll eat whatever I want' type of thing. Where in reality when it comes, you think 'oh, right, it is a big change really'. Even though it's only one tablet a day, it's what's round it that you have to change. (Terry)*

#### 10.2.4 Study 1 Self Identity

Self identity, symbolised by the boat, was a major theme, raised by all participants. In the metaphor the boat is not very substantial and this was intended to reflect those varying experiences. The sub themes of control, balance, compliance, empowerment and emotions, as shown in Table 10, impacted on and were influenced by participants' sense of self. Participants differed in their perceptions of control over or with diabetes, in the ways in which they achieved a balance between diabetes and the rest of life, how they felt able to comply with advice and the emotional aspects of living with diabetes.

Most participants stated that they did not want to be defined by diabetes; it was separate from their sense of self, although it also challenged their view of themselves. For example Rosemary was determined that she was not going to let diabetes characterise her:

*When I first was diagnosed we had a friend who was so into her diabetes I remember thinking 'I do not want to get like that' because she just, she talked about it all the time and was very openly sort of testing herself all the time and then talking about it. And it was just such a big part of her life I thought 'No, I'm not going to have that, I'm just going to get on with it' but took it to the other extreme I think. (Rosemary)*

Similarly Alan's experience of growing up with someone who "celebrated" his diabetes, meant that he too felt that he wanted to keep his diabetes low profile:

*I don't wear my difficult symptoms on my sleeve as it were. (Alan)*

Simon explained that he had never hidden the fact that he had diabetes and did not think that "*it makes me feel that different really*", while Albert was unhappy about being labelled:

*Well I didn't think I had diabetes when they told me I had diabetes. I felt as though they just labelled me with another illness. (Albert)*

In terms of control, most participants, with the exception of Alan and Anna, found managing their diabetes a struggle. Difficulties included, in terms of the metaphor, finding the right route, committing to a particular course of action, or setting high standards. These are described in more detail in the section on individual action but personal perceptions affected beliefs in achieving control:

*I guess I kind of see the goal of perfect control and I see it like so far away that I kind of almost, I try and do the next thing, the next step to get there but I guess there just feels like there are so many steps that it feels like it's never quite going to happen. (Simon)*

*And how much I'm willing like, if, I mean if I scared myself I'd be really controlled but how easy is it to just drift into borderline land and stay there for a long time, I don't know really. Not having been scared. (Rachel)*

Rosemary explained the paradox of finding life easier to manage if she did not comply with her diabetic regime, but how this also meant that this led to less control of her diabetes:

*And then I began to realise actually by not having as tight a control, it's more convenient for me and then it just slips. (Rosemary)*

Participants struggled to comply with advice and sometimes felt worse when they achieved what was expected of them:

*I rebel if anybody tries to advise me on what they think, cause I think 'when did you last read all the up to date research?'. (Rachel)*

*And I thought right, well I did try the diet sheets for about 3 months and then I didn't feel any better and I did feel lousy and I was beginning to think perhaps I have got diabetes"..... "I weren't feeling brilliant and I've been back and they said "oh*

*you've got it down to 7, well done". And I was thinking 'this is a lot of effort to get it down'. (Albert)*

Trying to comply led participants to feel guilty and, in some cases, they also felt blamed and incompetent. In addition participants described frustration, confusion, fear and anxiety:

*I guess it's quite frustrating sometimes ..... it becomes quite a battle all the time to sort of keep everything the way it should be I guess ..... why isn't it just really easy, why doesn't it just work .....maybe I resent it a little bit. (Simon)*

*But if I think about diabetes it scares me. (Rachel)*

*Generally annoying much of the time and I find that I am, as I'm getting older, I can't be as liberal with it as I was and I'm finding that difficult at the moment. (Rosemary)*

Only one of the participants mentioned depression. Rosemary discussed a situation where many difficult life events interfered with her ability to manage her diabetes. Her Diabetes Specialist Nurse had suggested a course of antidepressants and, although reluctant at first to admit that she needed them, Rosemary stated that they had been beneficial:

*That probably has helped me so that just the general level of anxiety was managed much better and that probably has helped quite a lot to find (pause) the, I suppose the emotional, the right emotional level to see this through as well, to do something about it. (Rosemary)*

Alan was an exception to the other participants in coming to terms with his diabetes:

*I think the main message is that separate from quite a lot of other people my diabetes is not a burden, it's something I live with and I'm quite happy with the kind of inevitable restrictions that making right choices brings. Yep. (Alan)*



### 10.2.5 Study 1 Individual Action

Individual action to manage diabetes is symbolised by the course through the choppy sea in the metaphor (Figure 22). The sub themes of information gathering and change are linked to self management. Participants collected and considered a great deal of information before trying out a particular course of action but also had to commit to the changes in order to self manage. Information was sought from sources other than the health service providers. Rachel and Anna in particular wanted to make decisions on what they considered the best evidence, and found this difficult:

*I read books about why it's a great idea and then I do it. And then I read another book that says 'no it's not a good idea, actually it's really bad for you'..... So it's lack of knowing what the best thing to do is I think that stops that being a permanent commitment. (Rachel)*

*Even when I'd been inspired and looked at things, it took me a while to decide what path I ought to take. And even when I started down a path I realised it wasn't going to be right for me. (Anna)*

For Simon it was about having an overall sense of which information was most relevant:

*I guess some things I've found, like some things I'm told now and find that work now mean that the way I thought used to be doesn't anymore. It's not necessarily adding to the jigsaw, it's kind of replacing some things or maybe adding and doing a bit of both I guess, which is quite confusing. (Simon)*

In order to make healthy eating and lifestyle choices, participants could only make changes by getting into the right 'head space' (of wanting to change):

*Now my head is saying I need to do something about it but also something inside me is wanting to do something about it which I think is the big difference to previously. (Rosemary)*

*I'm still trying to get it in me head that I am diabetic. You know, that you're not allowed all them sweets that you eat, you're not allowed all them biscuits. And maybe once I've got my head round cutting down, you know moderation, I have to change my mind set to get like that, you know what I mean. I can't do it overnight but maybe in time it'll come to it. (Terry)*

*It's got to be in your mind set for you that you're going to do it for whatever reason. (Anna)*

Not all participants were able to get to this point and some felt that it would mean having to give up too much. Simon and Albert summed this up in the following ways:

*I think I want to think differently but I just sort of don't and that's down to me, isn't it. (Simon)*

*So when, I mean I cut down on my potatoes and done this and that and I was trying to follow the diet sheet, you know reasonably accurately, I felt lousy and it hadn't cured me of me cravings. So I'd nick a biscuit you know, I'll just have a biscuit, it won't do any harm. (Albert)*

Participants needed to find their own routes and all tried out a number of different actions. For some this was trying different diets:

*So we're on the 5:2 diet and that's revolutionised me life where the diabetic sheets I was trying to follow were more about keeping it under control rather than finding something that would cure it or help. (Albert)*

*I think I've started it by my diet which to me is a big one, you know. I think the exercise will come. I will start doing more, I've got to start doing more. But I don't think, besides those two things and keeping meself healthy and fit, there's not a right lot else I can think of that I'm going to need to do because I wouldn't want to wrap myself in cotton wool, you know. (Terry)*

However participants found that changing diet was not necessarily straightforward or sustainable:

*And, you know, I went back on that diet loads of times but didn't manage to stick with it. So it's been a rocky road basically. (Rachel)*

*First of all I thought, well I looked into the Cambridge Diet, and going on meal replacements and I started at first thinking I'll do meal replacements and I tried that for .. probably perhaps 2 or 3 weeks and I thought there is no way I can carry on doing this. It will not work for me. I will have given up before I am anything like the weight I would like to be because I don't look forward to meal times anymore. (Anna)*

Some alterations to diet also involved changing lifetime habits, often culturally determined:

*But I have found a level of intake that suits me and I know I now will put half a plate of food aside if I've had enough. We weren't allowed to do that growing up (laughs). You ate what was in front of you and that was that. And that's actually remarkably difficult to stop doing. (Alan)*

As depicted in Figure 23, the environment, self identity and individual action were all interlinked. Participants' life events impacted on sense of self. Their values and beliefs filtered the knowledge they sought which then influenced action. Attempts to make changes affected participant's sense of control which in turn impacted on lifestyle.

#### **10.2.6 Study 1 Relationships with Healthcare Providers**

Relationships with healthcare providers were represented by the boatyard, which is off picture in the metaphor, Figure 22, and distanced in Figure 23. This was deliberate as most participants felt disconnected from the health professionals, although also acknowledged that they relied on them for support or monitoring. The sub themes of trust, power and communication characterised these interactions.

Trust was an issue when participants felt that they received conflicting information, had support denied or felt they were just being labelled. Simon struggled with differing advice:

*I think I started quite a while ago taking what I get told with a bit of a pinch of salt because one minute [medication name] is the amazing new thing that no diabetic should live without and then I get told by someone else that actually that's rubbish and I should be on this other one. (Simon)*

while Albert was concerned with what he described as “tick the boxes” medicine, which he found impersonal and unhelpful:

*They don't kind of understand that everybody's an individual and you have to manage everybody as an individual not just as a caseload. And it's just as though they can't be bothered or "we've ticked the box, you're a diabetic, just keep to the diet sheets or try different .." and (sigh) it's almost like containment. You're listed as a diabetic, well that's the sheet you should follow. (Albert)*

Acknowledging the limits on clinic times, Alan still felt that communication was one sided:

*I suppose I quietly think to myself if I never brought up any issue to do with my diabetes with the practice nurse or with my doctor, there wouldn't be anything coming the other way. I have to initiate it all. Apart from this one test a year where the nurse looks at my feet and prods me with a pin and that kind of stuff. But I don't remember the doctor ever having asked me how my diabetes is going or whatever. (Alan)*

Rachel tried to pre-empt development of diabetes by asking for blood sugar monitors but was refused. She saw this as a disincentive:

*I felt blamed for making an effort rather than encouraged. (Rachel)*

Similarly Rosemary compared going to see the GP with being summoned to the headmaster. She found the experience antagonistic and disempowering:

*Because I know if I go into the doctor's and just feel as though I've just been slapped over the wrist, the first thing I want to do when I come out is go and get a chocolate bar because I feel really quite sort of told off and it's not helpful. I find it quite stressful.* (Rosemary)

However Rosemary also talked about being supported by her Diabetes Specialist Nurse:

*She's brilliant, she's so patient (laughs). She's very, very supportive.* (Rosemary)

Anna was also able to give an example of where healthcare support worked for her:

*She's a good doctor. She's very kind. She's someone you can talk to and she just let me go away and she didn't say "well what are you going to do" and she just said "yeah, if you think". I think she thought I was intelligent enough to know sort of how to go about what I did and that's what I did.* (Anna)

What is clear, as shown by the dotted arrow in Figure 23, is that participants felt that healthcare professionals did not, on the whole, take into account individual lifestyles, life events and sense of self. To them it appeared that advice was directed at actions that the professionals thought were important, regardless of whether this suited the individual.

### **10.3 Study 1 Discussion**

This discussion focuses on the findings of the study and also on the use of the metaphor to represent the lived experience of the participants. It incorporates the comments from the participants who responded to the report on the findings. A more detailed theoretical discussion of Study 1 in relation to the

other two studies will take place in Chapter 13, where the implications for contribution to knowledge will also be considered.

The multi-component aspects of environment (physical, social and cultural, lifestyle and life events); self identity (including sense of control, emotional state and ability to comply with medical advice); individual action (information gathering and managing change); and relationships with healthcare providers all had impact. The participants' experience suggested that living with diabetes was a complex balancing act between managing or preventing diabetes on the one hand and trying to live a normal life on the other, supporting the findings of Ingadottir and Halldorsdottir (2008). Participants recognised the impact of life events on management and all were faced with possibilities and obstacles, as described by Andersson et al (2008). Barriers to management related to fitting it in to individual lifestyles (Hall et al, 2002).

Gomersall et al (2011) proposed that the complexity of assimilating information about diabetes could be seen as a threat to a person's sense of self. The impact of ability to assimilate information on self identity was not reflected in this study but certainly the very fact of having diabetes was. Alan considered this in his feedback:

*As long as the condition of diabetes is 'out there' as something 'other' or 'foreign' it will be a threat, something with which to fight, with which to be in constant conflict. The condition and the individual are not two but integrated and the degree to which they are integrated is the degree to which the individual is healthy. (Alan)*

Handley et al (2010) discussed the complexity of mastery over diabetes and similarly suggested that to be in control was to integrate or accept diabetes. The participants here all described the ways in which they felt that their own identity was affected by their sense of control, empowerment, ability to comply and by their emotional response to their diabetes.

The ability to handle the responsibility for self management (Minet et al, 2011) was also a factor described by participants. Those with type 1, in particular, described times when they could no longer be bothered to comply and both admitted that control was a very variable concept. Edwall et al (2008) considered the need for internalising mastery in order to incorporate diabetes into everyday life. Although it is acknowledged that managing diabetes on a daily basis can be difficult (Edwall et al, 2008; Handley et al, 2010), their research implied that there was a process by which people adapted to and were able to maintain control over their diabetes. However, the experiences reported here implied that this was not a linear process of mastery and that many life events 'knocked people off course'. As Rachel discussed in her feedback (below) change occurs all the time and it is likely that the concept of control changes from one day to the next.

Participants reported many interactions with healthcare providers but felt that they did not always get the individual support they needed to achieve successful management. This did not reflect the active involvement aspirations of Standard 3 of the National Service Framework for Diabetes (DOH, 2001) which called for integrating both the person's unique experience of diabetes and the 'doctor's'

agenda for shared understanding and decision-making (Stewart and Roter, 1989).

In his feedback on the interim report, Alan picked up on this point:

*There has to be a balance between imparting factual and technical information and a nurturing caring encouraging relationship, patient centred with those conditions of empathy, positive regard and non-judgement. (Alan)*

Rachel also raised this as an issue in her feedback, indicating that current attitudes from healthcare staff resulted in disempowerment and a possible lack of compliance:

*The holistic approach makes it clear that blame is inappropriate and that labelling someone as coping poorly is a mistake – changes are occurring all the time. We have some influence on health, but not total control. If health professionals took the whole of life into account and listened to the experience and journey of people with diabetes, they would have more chance of promoting positive health behaviours. (Rachel)*

There were some examples of good supportive healthcare but many participants talked about being unable or unwilling to take advice (Funnell and Anderson, 2004). This related to mistrust of information received, and care plans or advice not fitting into lifestyles, as suggested by Funnell and Anderson (2004). For example, participants were given particular diet sheets or recommendations to increase activity levels but this narrow focus on reducing risk factors did not always suit individuals. Although Gillies et al (2007) argued that compliance was the key to successful lifestyle intervention, strategies suggested by healthcare professionals were not those that participants would necessarily choose and thus were likely to lead to non-compliance (Anderson and Funnell, 2010). Feeling belittled by healthcare staff also had an impact on compliance for the participants, notably for Rosemary who admitted to rewarding herself with



chocolate to make herself feel better after a particularly negative experience with her GP.

Although compliance with test results (blood glucose, blood pressure and cholesterol) was seen as important, getting on with life was prioritised. Stuckey and Tisdell (2010) noted that a concentration on numbers (test results) was not helpful for those living with diabetes, as it led to a negative focus. This suggests that consideration is required as to what outcome should be used to determine improvement in diabetes health and wellbeing. A focus on biochemical tests (Brackenridge and Swenson, 2004; Gilis-Januszezowska et al, 2011; Matthews, 2007) might not meet the individual's agenda. Outcomes on health related quality of life (Barbosa et al, 2011), which is what the participants were striving for, may also be required.

### **10.3.1 Study 1 Representation of the Lived Experience through Metaphor**

Although ongoing participation was voluntary, three of the participants in this study commented on the use of the metaphor (Figure 22) to report and represent their experiences. Their feedback was considered to be valuable in understanding the overall concept of the lived experience. Anna identified with the metaphor describing *"having been tossed about a sea with my diabetes for a long time"*. She reported that *"it does make a difference when you have hit calm seas"*, clearly showing the ups and downs and range of conditions she had experienced.

Alan commented that “*firstly I think the metaphor works very well*” and then went on to analyse the artwork itself:

*My first view of The Boat [self identity] was that it was too frail and fragile and could not possibly survive the gales and turbulence of the wild ocean with all its elements. I would like to see The Boat having the capacity to grow into robustness as the creative elements are encountered and embodied by the patient. (Alan)*

This brought new insight into the need to focus on individual strength and resilience to manage both life and diabetes in a way that could lead to health and wellbeing.

Rachel reiterated this viewpoint and stated that she felt that the metaphor was useful as a visual representation of:

*how environmental demands and challenges can influence health behaviours, health related choices and the ever changing nature of the coping skills needed. It also implies that diabetes is just one aspect of life and sometimes has to take second place to other issues as they crop up. (Rachel)*

Creative metaphor has been used to establish meaning in supporting and understanding people with diabetes (Stuckey, 2009; Stuckey and Tisdell, 2010) and the feedback from these three participants suggested that creative metaphor was an appropriate and helpful way to encapsulate their experiences and gave them the opportunity to make further comment.

## **10.4 Study 1 Summary**

This chapter has described the findings of study 1 and discussed these in relation to the literature on the lived experience of diabetes. The use of metaphor to conceptualise that experience has also been considered. The findings, and

feedback from participants on those findings, indicate that living with diabetes is not just about achieving optimum test results but about balancing out the requirements of diabetes management with the wellbeing of living a normal life. This suggests that a holistic, non-judgemental approach is required to understand the impact of life events and self identity on enabling resilience to manage that balance. The next chapter reports the findings of Study 2. The following excerpt reflects on the process of creating the felted sea metaphor.

*Reflections on creating the felted sea metaphor:*

*I went back to the Kincheloe and McLaren chapter and to bricolage and a sentence sparked off what felt like a bit of a breakthrough - although sometimes it's hard to know whether this is just fanciful (why the supervision team is so important to bounce these ideas off). It was about the bricoleur attempting to understand the fabric and the processes which shape it (2005, p320) - they were referring to the social fabric and rigour - but this seemed to me to be analogous with the felt making: from a process point of view the felt making (alpaca) attempts allow some understanding of the fabric - it doesn't react in the same way as merino; it needs more forces applied, bits drop off but stitching brings a new facet - colours, shapes, thickness. It becomes something else from the bits of wool that were originally there. The sheering of the fur is like the info shared by the participants, it is manipulated (wetted, soaped, rolled, examined, rolled again in different directions), examined both sides, a decision is made about which way is up. The salient features are highlighted through stitching, the themes through free sewing, what is the end result? It's not a standardised treatment because it depends on the materials in the first place and also on the knowledge and skill of the felt maker (researcher). I then looked at the other (merino) felted piece and saw a tossing sea and found my metaphor for the first stage of the research - that the lived experience of diabetes (or pre-diabetes) is like being tossed about on the open sea:*

*I found a skeleton leaf which I cut into the shape of a boat - deliberately featherlike. The boat is the 'anchor' around which the identity of self is*

*established (it becomes more substantial) and through which some control can be steered and the waves are the forces or context that push and pull, ebb and flow, some can be ignored, others are deep and worrying. The ninth wave represents the left field symptoms, the unexpected. Not every sailor experiences this. But the sea is rarely calm.*

*It seemed to me to be an almost magical progression through the artwork from the notion of the data being cut up into pieces (as in the coding work) to this complex felt picture of the boat on the storm tossed sea. May be this is the next stage. What do people's seas look like? How strong are their boats? Who is the crew - family and significant others? How else might people be visualising it? How can this transform our understanding and support?*

*I feel excited by this and then doubt creeps in - how do I know this isn't researcher bias? How can I be sure that this is the end result of an analysis of data and reflexivity? I think back on previous attempts at coding and theming, line by line, categories, themes, connections, comparisons, followed by the forcefield analysis, and then trying to fit the data to the OT theory - the MOHO and the Ecological Model of Occupation, and then abandoning that and going back to the data once more. Then abandoning the data and reading through the research methodology where once again things started to chime and the data became alive again. Then wanting to give a voice to that data through the doctoral colloquium and feeling the need to write to the participants to report on what has happened but being mindful of my bias as an OT researcher.*

*I started to examine the metaphor from all sides to see if it fits - is there anything wrong with it? It feels comfortable because it doesn't appear to channel the experience of the participants into the more linear - struggle, take control, maintain control - themes which highlight the current lived experience literature. Also it's not necessarily a metaphor that I would use (gardening and walking would be more likely ones). I am not a sailor in the conventional sense but I too sail through life. (June 2013)*



**Figure 24 Headspace**

*I played around with photographs of my profile in Photoshop Elements with different textures to symbolise 12 different 'head spaces'. I then cut them out and glued them to cardboard with different papers on the right and left of each head - thus providing 24 different versions. I then attached them together making a concertina out of cardboard.*

*This piece is a critical reflection on myself as researcher and represents the different selves I bring to the research. Who are they? My self as practitioner, theorist, researcher, wife, friend, sceptic, daughter, artist, political being, student, teacher? The self I started in the research journey, the selves I become in the journey? I pondered on the impact of these selves on the research and the impossibility of separating them, or knowing which self I was bracketing out and which I was potentially leaving.*

# **11. Study 2 Findings and Discussion**

## **11.1 Chapter Outline**

This chapter describes the findings of Study 2 Living with diabetes: an occupational therapist's perspective. Due to the large amount of data produced and the variety of topics covered, this chapter is divided into sections. After the introduction the first section covers the use of metaphor in understanding the experiences of diabetes. The next section considers the role of occupational therapy in diabetes self management. For ease of reading, discussion of these findings is integrated into each section. In line with the colour coding introduced in the Study Design chapter, all findings tables for Study 2 are in blue. The theoretical consideration of the findings of all three studies and the links between them will be examined in Chapter 13.

## **11.2 Study 2 Introduction and Participants**

This second study sought to understand the perspectives of occupational therapists living with diabetes. Following on from the first stage, this study explored the metaphors that participants used to describe their experiences of diabetes and how metaphor might help understanding of this condition. In addition this study aimed to investigate what these occupational therapists saw as the role of occupational therapy in the management of diabetes. This latter aspect involved how participants might apply occupational therapy principles and practice (WFOT, 2012) to their own diabetes self management and what they saw

as the role of occupational therapy for others with diabetes. This section describes the participants.

### 11.2.1 Study 2 Participants

Ten occupational therapists (nine from England and one from the USA) with a diagnosis of type 1, type 2, pre-diabetes or gestational diabetes were recruited to the study. All names used are pseudonyms. Table 11 shows the demographic details of the participants. All participants were currently employed in a variety of occupational therapy roles and most had had a number of posts in a number of different practice areas.

Pseudonym	Diabetes type	Length of time since diagnosis	Age
Nancy	Gestational diabetes	11 years ago	52
Helen	Pre-diabetes	< 1 year	53
Martin	Pre-diabetes	< 1 year	41
Frances	Type 1	41 years	48
Jill	Type 1	22 years	47
Karen	Type 1	27 years	37
Susan	Type 1	32 years	36
Carol	Type 2	9 years	50
Jessica	Type 2	10 years	53
Vanessa	Type 2	< 1 year	53

**Table 11 Demographics of Study 2 Participants**

As this is a relatively small occupational therapy practice community, work details are summarised generally rather than individually in Table 12 to maintain anonymity.

Work roles of occupational therapists	
Years practising in OT	1 – 33 years (mean 21.9 years)
Practice areas (previous or current):	Education Learning Disabilities Management Mental health: adult, older adult, (in-patient and community) Paediatrics Physical health: A&E, acute, burns, cardiac rehab, elderly care, HIV and AIDS, orthopaedics, palliative care, rehabilitation, respiratory, stroke, surgical, wheelchairs (in hospital or community based)

**Table 12 Work roles of occupational therapy participants**

Eight of the participants were married with families and had a number of roles to manage. The other two, while single, had family commitments. Nancy's gestational diabetes (IDF, 2013a) had occurred eleven years previously but she recognised the fact that she was at increased risk of developing type 2 diabetes.

Helen and Martin had both been diagnosed with pre-diabetes (Mainous III et al, 2014) within the previous twelve months and both were keen to make changes to try to prevent developing type 2 diabetes (Narayan et al, 2002). Martin discussed his experience of a few months of unidentified ill health and that his diagnosis was both a shock and a relief. Helen stated that she had similarly experienced periods of not being quite well and had had numerous trips to the doctor before her diagnosis. Like Martin, for Helen there was some relief that the symptoms had not signified something worse and the diagnosis gave her the prompt she felt she needed to make changes to her lifestyle.



Frances, Jill, Karen and Susan had had type 1 diabetes (IDF, 2013b) for many years. With the exception of Jill, all had developed the condition in childhood and had gone through phases of rebelling against their diabetes as they grew up. Jill's diabetes had been diagnosed at work and she described her management of diabetes over the years as having been erratic.

Carol and Jessica had both had type 2 diabetes for a number of years. Carol had had gestational diabetes in both pregnancies before being diagnosed later with type 2 diabetes. She described fear (of injections and future complications) as a motivator for managing her condition. Jessica, by contrast, admitted that she did very little to manage her diabetes, preferring to ignore it where at all possible. Vanessa had recently been diagnosed with type 2. Like others she had gone through a period of not feeling well and had been surprised at the diagnosis, but had used the diagnosis as a stimulus to make lifestyle changes.

### **11.3 Study 2 Metaphor preparation, usefulness and analysis**

This section first describes the metaphors that participants prepared prior to the interviews, the themes related to generating the metaphor and the usefulness of metaphors to understand diabetes. This is followed by an analysis of the metaphors used generally in the discourse of the interviews to explore more widely these themes.

### 11.3.1 Study 2 Prepared Metaphors

Prior to interview participants had been asked to prepare a metaphor (Gauntlett, 2007) – a picture, a poem, a photograph, an object, or something of their own creation – which encapsulated their experience of diabetes. Participants' pre-prepared metaphors were analysed in terms of generating the metaphor, the metaphor itself, and its usefulness. Individual metaphors are discussed first, along with the explanations that the participants provided. Five of the participants brought along pictures to help explain their metaphors. Table 13 summarises the range of metaphors.

Nine of the ten participants prepared a metaphor. Karen reported that she had been unable to come up with a metaphor, explaining that:

*I can describe what my diabetes is to me but I can't think of anything that [is].... like it, because to me my diabetes is there, well it hasn't always been there, but it's been there since 10, it's a little part of my life, it's who I am. (Karen)*

The following brief excerpts, introduce and then explain the metaphors in the participants' own words.

Nancy prepared a photo-collage of those aspects of managing her gestational diabetes that were significant to her. This involved looking for objects such as her meter, lancet, strips and a leaflet about managing her condition and she reported that it was important to arrange the objects to create a collage that focussed on what she needed to do at the time.





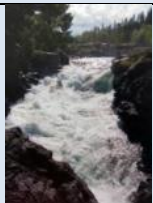



Pseudonym	Metaphor	Picture (where applicable)
Nancy	Collage of experience of gestational diabetes	
Martin	Picture of face Acronym of food	 
Helen	Taking the right path	
Frances	Another layer of skin	
Jill	White water kayaking	 
Susan	Tug of War	
Karen	No metaphor	
Carol	Slimming World Booklet Photo of cup cakes	 
Vanessa	Competition / Steeple chase	
Jessica	Untidy house	

Table 13 Metaphors prepared prior to interview by Study 2 participants

Nancy explained that one of her twin fetuses had died at 4 months, shortly after which she had been diagnosed with gestational diabetes, and the photographs of babies in the womb, which she had found in a book (Nilsson, 2010), symbolised this time. She found that it gave her the opportunity to reflect back on that time and on how strong her motivation had been to manage her diabetes to ensure that the remaining baby survived:

*I thought a lot about the metaphor, got the picture taken and then played around with several different things to put it together. I think what it meant for me was a kind of looking back and seeing that I was able to put that kind of focus into what was needed to be done and that was very important and motivating, certainly it was a kind of reaffirming, a validation of the love I have for my daughter..... So it's a little bit of past, present, future kind of reflecting through putting that metaphor together. (Nancy)*

Martin reported that his metaphors came to him straightaway. He drew a picture of a face and prepared an acronym to represent two different aspects of his diagnosis that were significant to him. Martin feared that his ill health prior to diagnosis might have been related to something that he considered much more serious so when the news came he was both relieved and shocked, which he represented on the face. Martin also thought about his on-going battle to manage his weight over the years and his relationship with food which, he explained, might have led to developing pre-diabetes:

*So on the one half you've got the smiley face which is the relieved half of my face and on the other half it's supposed to show the shock of being sort of delivered the news that I could be close to being diabetic type 2..... I also thought, I think for me, it's all about food... I've just written that - F.O.O.D - Friend Or Our Downfall..... I love food but where it's my downfall is eating too much of it and at the wrong times and treating it wrongly. (Martin)*

Helen planned a picture on which were printed six images of paths. Her metaphor represented her need to take the right path following diagnosis. She reported that she had found it difficult to come up with a metaphor but that once she had decided on the paths she felt it signified the choices she was faced with and the need to stay on what she saw as the “good path”:

*Well I've got a selection of pictures that basically it's like you're travelling a path and then you can go one way or the other, there's all this choice. I've got one that says success and failure, but actually it's not, well it is sort of success and failure but it's more the good route or the bad route. I felt this is where I was last year and I'm on hopefully the right side ..... it's got to be one or the other. .... it's very much two, one way or the other, which way you're going to go and this is the path you then must then stay on. (Helen)*

Frances reported that she had tried out a number of metaphors such as putting on a jumper or other clothes but then thought that she could take these off and realised that this was not the right metaphor for her. She decided that her metaphor was “another layer of skin”. This was significant for Frances in that she felt that her diabetes did not just sit in her pancreas but had the potential to affect the whole of her life, although it did not limit her. She reported that she had found the metaphor interesting to think about and that it felt right:

*And the way I described it is like another layer of skin for me in that, I remember as I described, having to put it on, taking on the additional responsibilities and understanding I will always have an additional part of me that needs to be looked after. So a bit like you moisturise your skin, a bit like you wash your hands, all of this you're looking after yourself, well mine is another layer, I just have to do a bit more. I can't take it off so I can't put it down and forget about it. You have to look after it, if you don't you feel and will eventually see the effects of it..... It affects, or I suppose it can affect, any part of me but I suppose because it does, or has the potential to affect my whole life, is why I thought it is all over me. But it doesn't feel like it's a constraint. (Frances)*

Jill was the only participant of this study who had already seen the sea metaphor from study 1 prior to interview. She explained that she had tried a number of metaphors such as cycling or growing plants but had returned to the sea metaphor to adapt it. Jill explained that she did not have a choice with her diabetes and that she was instead following a particular route, as in a river, and that she could not get off. She explained that her metaphor was all about balance and control and her attempt to accept that she was not going to be able to manage it well all the time. She reported that she had found it satisfying to find something that she felt encompassed all aspects of her diabetes:

*I thought actually it's a bit like kayaking. And I thought you've got the element of balance, you've got the direction, you've got a bit of downhill, it's very very variable depending on conditions that are out of your control, whether that's weather conditions or flood conditions or, and those things that I talked about before coming in from left of field but they still have to be managed and they still have to be worked with, you can't ignore them because they don't go away. These are things going on [indicates diagram] and times when actually, I've got a picture here which is (laughs), there's a little kayak there and it can sometimes feel a bit like that, where everything is just wild and foamy and steep and perhaps not feeling very in control and you can have very high sides sometimes, you can have gorges ... In terms of the kayaking there's the challenge of it, it's not easy. And you can rise to the challenge or you can ignore the challenge (laughs) but I think if you ignore the challenge you end up in the foamy steep water..... I suppose I've had times when I have capsized and I have climbed back in my boat, slightly wet, slightly cold and carried on.....it's still a journey and it's not one where you can think 'right I'm going to stop now' because that's not an option. So it's a long journey. (Jill)*

Susan's metaphor was based on Acceptance and Commitment Therapy (Hayes and Strosahl, 2004). She explained that she had seen a video or diagram of the metaphor, had liked the creativity of it and felt that it fitted with her situation. Susan reported that her metaphor was fundamentally about the struggle of life

on many levels, her realisation that 'normal' did not exist and her need to be more accepting of her situation:

*The Struggle – if we want to call it a struggle is like that of the tug of war game. The 'demons' of our diabetes at one end and us the other. When we pull tight the demons come closer, when the demons are pulling tighter we are pulled towards them. Whoever is winning the demons are always either being drawn closer or we are being drawn closer to them. No one really wins. You just need to let go of the rope so there is no struggle. Fight over. Learn to accept the diabetes and the demons and life is easier to handle..... it more represents a struggle of constantly trying to be perfect, I don't know if any of the other people with diabetes, but we're always, always wanting to have good blood sugars and to be the perfect person, be the perfect daughter or be the perfect OT, you know..... I think I've spent too much of my life trying to follow the rules, you know, and trying to stick to the rules to be, to get it right and it's like the metaphor, let it go. (Susan)*

Carol reported that she had found it hard to generate a metaphor and that she had spent some time thinking about what she could bring to the interview that represented important aspects of her identity. She decided that her Slimming World® booklet represented her journey in losing weight to improve her diabetes management. The picture of cupcakes represented her love of food and baking and the potential conflict between that and slimming. Carol reported that she saw both of them as very much part of her life:

*So this is my Slimming World book which I brought in. It is the second Slimming World book I've had, it doesn't indicate, I was 13 stone 6 when I started and last week I was 11 stone 12. So I want to be 10½ ish in my head. So yes, so this is kind of like, that's my whatever it is [metaphor] you wanted to know..... Well interesting the other picture of course is, I'm a great baker..... But this is very much part of my life at the moment. (Carol)*

Vanessa also reported that she had initially found it difficult to come up with a metaphor but after thinking about it for some time had decided that the

competition element was important and then refined this to the metaphor of a steeplechase. She explained that her experience was very much around control. The hurdles and water jumps represented other health issues which could threaten her sense of control and which she was sometimes battling but it was also important for her to meet the challenge:

*It is a competition, myself v diabetes, a battle and I am winning. I am in control and will not be beaten. I am stronger and healthier now than I was before diagnosis..... it's a bit like the steeple chase, as a race in that you are kind of going round and round, so that's the ongoing lifelong nature of it. It's an endurance event, it's not a kind of quick sprint. And then you've got hurdles and water jumps on a steeple chase. So you have to get yourself over things and so those for me are things where my health goes off. (Vanessa)*

Jessica admitted that she thought that the idea of generating a metaphor was “*slightly barking*” to begin with and had thought it would be difficult to do. She explained that when she was trying to think of metaphors she thought that guilt came into it as she felt she should be managing it better. She reported that the metaphor of an untidy house had then “*arrived*” and when she started to consider it she felt it made sense. For Jessica her metaphor reflects her busy lifestyle and attitude to diabetes, which on the whole she ignores. She explained that the metaphor was around not putting her house in order and the guilt that she should be managing her diabetes better:

*I was kind of thinking somewhere along the lines of comparing it to my very untidy house which kind of fits with my lifestyle really (laughs) and thinking that partly I've only got myself to blame that it's in such a mess ..... I thought about it as an incentive to clear the place up but on the whole I just ignore it and hope it will go away (laughs) so that's kind of how I was comparing it really. And then every now and again I have a major clear up when somebody might be going to notice (laughs) which also fits with the diabetes, if that makes sense. (Jessica)*



It can be seen that the response to generating metaphors was mixed. Five out of the ten participants reported that they found this difficult. Four of those five persevered to find something that they felt conceptualised their experience of diabetes. Participants talked about how they generated ideas for metaphors in terms of inspiration, trying out, and/or discarding ideas, and reflection. It was important that metaphors expressed participants' self identity (eg good fit with sense of self or with using aspects of self such as creativity). Most participants reported that it had taken some time to come up with a metaphor and some recognised that their own metaphors might have changed over time. Reflecting on their experience they stated that their metaphor would have been different a year ago.

Clearly there are some shared meanings across the metaphors in terms of struggle, control, achieving a balance, choices, journey, motivation and responsibility. This is considered further in the discussion in section 10.5. However each metaphor is unique to the individual and indicates that participant's particular experience.

Overall, despite some initial doubts, all participants (apart from Karen) found the experience of using metaphor interesting and useful to:

- make sense of the experience generally and personally
- examine and reflect on the main issues
- understand aspects of diabetes that hadn't occurred before

- find satisfaction at finding a way of encompassing all aspects of the diabetes experience.

Radley (1995, p.119) discusses the way in which metaphor makes a person's health condition "*viable and comprehensible*". The metaphors that participants chose to share in the interviews certainly revealed their different situations and gave insight into the particular aspects that most concerned them (Cameron, 2003; Czechmeister, 1994).

The concept of controlling or being controlled by diabetes appeared in the three sports metaphors of the steeple chase, white water kayaking and tug of war, and also in the metaphor of the untidy house. Ingadottir and Halldorsdottir (2008) reported a similar situation where participants struggled with their diabetes, either allowing it to control everything, to fight it or to ignore it with a corresponding lack of control. For one of their participants this was summarised metaphorically as "*the relationship between a dog and his master*" (Ingadottir and Halldorsdottir, 2008, p.610). Another participant in their study described her diabetes as "*an uninvited companion*" (Ingadottir and Halldorsdottir, 2008, p.615). Interestingly the value of participants' metaphors is not highlighted specifically in their research, although the concept of mastery of diabetes is explored.

Zaltman and Zaltman (2008, p.175) discuss an example of diabetes control which mirrored Susan's experience. "*I feel in a tug-of-war. Diabetes is pulling one end of the rope and I am on the other end. We are each seeking victory, pulling the*

*other into our control*". In Susan's metaphor she learned to let go of the rope. This was not to give up but paradoxically she found that by not 'fighting' her diabetes in the tug of war, she got the control back in her life.

Helen's metaphor of 'taking the right path' was a journey metaphor but unlike those metaphors discussed in the Literature Review (p.87) of people being stuck and immobile (Fullager and O'Brien, 2012; Mallinson et al, 1996) or being without destination or map (Frank, 1995), she emphasised the constant moving forward, endurance and importance of taking the right route to success. These themes also appeared in the steeple chase and kayaking metaphors.

The other metaphors in this study reflected the need of participants to find something that represented an aspect of their identity. Whincup (2004) suggests that the objects and pictures that people keep have special meanings in terms of self identity and construction of identity. The pictures that participants brought or created to talk about their diabetes (collage of gestational diabetes, Slimming World<sup>®</sup> book, the face) appeared to encapsulate aspects of that identity. Nancy talked about her need for the collage to tell the whole story. The objects represented were symbolic of her motivation, her focus on what needed to be done, a means of reflection and a reaffirmation of her love for her daughter. Nancy also talked about her need to arrange the objects of her collage in a meaningful way to clarify their significance for her, reflecting the work of Whincup (2004) and Gauntlet (2007) who both found that the way people organised objects was symbolic of creating a unified whole to represent their

identities. For Carol, the Slimming World® booklet and photograph of cupcakes were symbolic of 'this is who I am' (Gauntlett, 2007) which for her appeared to be the priority over diabetes. Martin's smiley face, showing the shock and relief of diagnosis, went to the core of his overwhelming emotions at the time. In addition his acronym of FOOD (Friend Or Our Downfall) enabled him to focus on what for him was the heart of the issue and to explore this in the interview. 'Putting on another layer of skin' for Frances represented taking on additional responsibility. Frances had tried a number of metaphors before this one and this metaphor had clarified precisely what her diabetes meant to her (Gauntlett, 2007). She was also keen to ensure that the researcher did not make inferences about her metaphor (Cameron, 2003) by explaining that *"it wasn't like some Doctor Who thing that gets tighter and tighter and tighter"*.

Asking participants to explain the prepared metaphors that they brought to the interviews enabled understanding of their experiences, emotions and attitudes (Cameron and Maslen, 2010). Participants reported that thinking about the metaphors had been useful to them and enabled them to focus on the main aspects of their diabetes experiences. As a research tool it was also helpful for allowing a unique insight into that experience (Cameron and Maslen, 2010). However it must also be acknowledged that one of the participants was unable to come up with a metaphor and thus not everyone will feel comfortable with using these directly. Karen responded to the interim report to say that:

*I certainly don't mind you talking about my lack of metaphor. It has been interesting to read the language other people have used and how we all have said some similar things. (Karen)*

Nancy similarly replied that:

*The metaphors and use of language was quite powerful!* (Nancy)

### **11.3.2 Study 2 Metaphors Used Within the Discourse of the Interviews**

It became apparent when analysing the interview transcripts that metaphors were used liberally in the discourse. All metaphors, related to both diabetes and occupational therapy were analysed using a form of metaphor analysis devised by Cameron and Maslen (2010). See Chapter 9 Study Design for details. Metaphors across all interview transcripts were identified and grouped into common source domains (Kosvecses, 2002). Table 14 gives examples of all metaphors used by all participants and their allocation into these source domain vehicle groups. These metaphors of everyday language were then analysed according to the context in which they were used: diabetes diagnosis; diabetes self management; diabetes general management; life experience; lifestyle; occupational therapy. The metaphors related to occupational therapy will be examined in section 11.4. Table 15 summarises the number of metaphors used in each of these contexts. As can be seen in Table 15, metaphors were used less frequently to describe life experience and lifestyle. However these metaphors had significance for the individual participants. The most frequent use of metaphor was in relation to diabetes self management.

Vehicle grouping (source domain)	Metaphors collected into the grouping
ART & CRAFT	cotton, picture, sewn, woolly
BUILDING/ CONSTRUCTION (including materials)	barrier, build, door, fence, floor, foundations, frame, framework, ground, grounding, hotel, key, layer, line, polystyrene, rails, (back) shelf, solid, stable, stand, street, structure, supports, tower, underground, window
CONNECTION	best friends, embrace, hold, touch, relationship
CONTAINER	(in) box, fill, (out of) hands, (in) (enter) (out of) head, headspace, (in) heart, label, (back of) (into) mind, mind's eye, occupying (particular thing), package, place, soap box, (right) space, sit (in)
EDUCATION	headmistress, put hand up,
FOOD / COOKING	consumes, consuming, consumed, cut/dried, distil, mix, set, sweet tooth, tea, watering down,
FORCES	break, break down, breaking, budge, builds up, bump, chaos, crashing, dominating, drag, empower, energies, fluid, hard, heavily, heavy, hit, hot, kick, knock back, lean on, nudge, positive, power, powerful, pressure, pull, push, pushed, pushing, reign in, rub off, shock(ed), shove(d), slap, storm, stress, stretch, strike, struck, sucks, turbulent, upheaval
GAMES/SPORT	back foot, ball game, bet, catch, chance, clue, cue, deal, game, jump, kicked, net, pitch, racing, rules, ran, run(s), running, spot, tackle, target, threw, throw, track, treading water trigger, waterslide, yoyo,
MACHINES / TOOLS	band, checks and balances, conveyor belt, crutch, cycle, cylinders, device, driven, equip, equipment, focus, lens, line, rake, rocket science, rocket, scale(s), scope, scratch, slots, solid, stable, stick, systems, ticking, tool(s), unpick, vaccine, weigh up
MILITARY	activate, bang(ing) the drum, battle, battling, beat, bombarded, call up, discipline, fight, fought, over the top, radar, rebel, regimented, shoot, struggle, taking over, threat, trigger(ed), Wild West, wrangle
MOVEMENT/DIRECTION	above, all over, back, bit by bit, coming at, course, creep, depth, direction, distance, down, downhill, driven, drop, dropped, end, escalating, fall, fall apart, fall out, flip, forward, from, get to, heading, high, higher, journey, laidback, low, moving, navigate, near, on board, off, over, pace, pans out, path, pathway, peak, route, scale, send, set back, shuffle, slip, slope, spike, standstill, step, there, trotted, under, up, uphill, up to, went,
NATURE includes landscape, light/dark, plants, animal	background, borderline, beast, bees knees, burrow, clear, colour, confluence, crop, floods, fresh air, fresh, middle ground, pear shape, plateau, quagmire, shade, skunk, star, stems, watershed, weather
RELIGION	devil, ecumenical, hell, religiously, vision
RESOURCES	blank canvas, bundle, burning (candle), catalogue, cost, end of, feeds, fill need/gap, find voice, fuller, half, last rolo, lesser, load, number, out of pocket, per cent, resources, rubbish, saver, string, switch off, tied, took stock, undermined, wears off
WARNING	bells ring, rang, wakeup call

Table 14 All metaphors used by all Study 2 participants and their groupings

Context	Total metaphors	Top two vehicle groups and number of instances	Metaphor examples
Diabetes diagnosis	20	Movement / direction (6)	<i>Start of a journey</i> ; early intervention to <i>move</i> blood sugar levels; <i>fall out</i> implications of diagnosis
		Forces (5)	<i>Shock</i> of diagnosis; diagnosis <i>empowering</i> individuals
Diabetes self management	229	See table 17	
Diabetes general management	73	Movement / direction (11)	Prescribed <i>pathways, routes</i> ; GP surgeries being diagnosis <i>driven</i> or in certain ways; Blood sugar level readings being <i>low, high, all over</i> the place
		Military (10)	<i>battling with</i> or being <i>taken over</i> by diabetes; being <i>bombarded</i> with information; approaches not being on healthcare professionals' <i>radar</i>
Life experience	10	Forces (3)	Aspects of life described as <i>chaos, heavy, turbulent</i>
		Machines / tools (2)	Along the <i>line, stick</i> thin
Lifestyle	17	Building / construction (5)	Putting self on <i>shelf, back shelf</i> ; finding <i>supports</i> ; home like <i>busy hotel</i>
		Forces (4)	Lifestyle feeling full of <i>pressure, stress</i>

Table 15 Metaphors used by participants in relation to context

Movement / direction (n=80) metaphors (used by all participants) included the following:

- [Blood sugar being] low, high, up, down, top, spike, peak, escalating, running high
- Making progress towards, having a way to go
- Being internally driven or stepping up to make changes
- Letting self down, not wanting to slip back
- Mood being low or all over the place

Container (n=26) metaphors included:

- Getting in the right headspace, sorting things out in one's head
- Ideas for self management going in, out of, at the back of head / mind
- Putting thoughts / plans in boxes
- Getting into a better emotional place
- Having labels applied

Games / Sports (n = 26) metaphors included:

- Setting targets
- Getting on / falling off track; things running smoothly (or otherwise)
- Clues and rules of diabetes management

Table 16 gives a more detailed example of the analysis of this particular context showing the range of source domains used, numbers of instances and an overview of how many of the participants used these particular metaphor groupings. Examples of the metaphors within the three most frequently used vehicle groups in this context are given.



Diabetes Self Management		
Vehicle Group (Source domain)	No of instances	Used by Participants
Art & craft	2	Vanessa, Karen
Building / construction	7	Frances, Jessica
Connection	2	Karen, Jessica
Container	26	Carol, Frances, Martin, Vanessa, Helen, Nancy, Karen, Jessica
Education	2	Jill, Helen
Food / cooking	1	Nancy
Forces	17	Martin, Jill, Susan, Vanessa, Helen, Nancy, Karen, Jessica
Games / sport	26	Carol, Frances, Martin, Jill, Susan, Vanessa, Karen, Jessica
Machines / tools	11	Carol, Frances, Martin, Nancy, Karen
Military	21	Frances, Martin, Susan, Vanessa, Nancy, Karen
Movement / direction	80	Carol, Frances, Martin, Jill, Susan, Vanessa, Helen, Nancy, Karen, Jessica
Nature	12	Carol, Frances, Martin, Jill, Nancy, Karen
Religion	2	Jill, Nancy
Resources	18	Carol, Frances, Martin, Jill, Vanessa, Helen, Nancy, Karen, Jessica
Warning	2	Carol
TOTAL	229	

**Table 16 Details of metaphor vehicle groups used to describe Diabetes Self Management**

The more general metaphor analysis of the interview transcripts certainly revealed, as those participants fed back, the interesting and powerful use of language. However caution must also be expressed in the analysis of the use of identifying many of the conventional phrases that were used by participants. Cameron (2010) suggests that these are often not recognised as metaphors by the individuals using them and thus assumptions cannot be made about the significance of their use. It may instead be more useful for the researcher or practitioner to listen out for the language and metaphors used in the course of

conversation and to explore these and the context in which they occur (Cameron, 2003).

### 11.3.3 Study 2 Visual Representation of the Metaphor Data

A way of visually understanding the metaphor data was sought to get a feel for its meaning. The data was entered into Wordle<sup>®</sup> to create word clouds, which give a clear indication of the relative values of the metaphors used in general. The following word cloud (Figure 25) consists of all metaphors used by all participants in all contexts (as listed in Table 14, p.222).



Figure 25 Word cloud representation of all metaphor groupings

The word cloud in Figure 26 shows the relative use of metaphors in the context of diabetes self management, reflecting the information in Table 16.

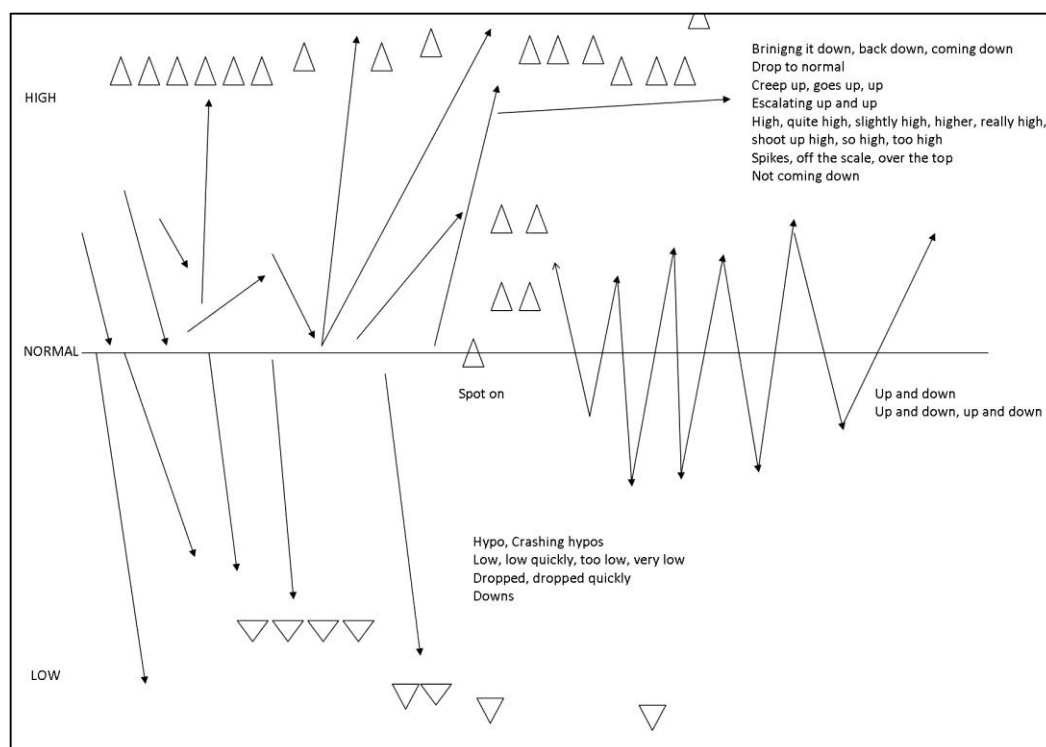


Figure 26 Word cloud representation of metaphor groupings related to diabetes self management

Clearly metaphors for movement/direction are quite extensive and thus an attempt was made to represent visually the particular movement/direction aspect of trying to balance out or get blood sugars under control. Figure 27 shows the movement/direction (up and down) and stated points in relation to the metaphors used (which are indicated on the diagram).

Figure 27 gives some sense of participants' experiences of attempts to control blood sugar levels. At times participants felt they were able to bring high levels down to normal but many times reported that, despite their best efforts, sugar levels crept up from normal or escalated in an alarming way, remaining very high. At other times sugar levels appeared to oscillate between high and low with only one instance reported of blood sugar levels being 'spot on' (Montez and Karner, 2005; Rasmussen et al, 2007). While most examples noted in the interviews reflected high levels, participants also reported times when blood sugar levels "*crashed*" or "*dropped*" to low and hypoglycaemic levels (Farmer et al, 2007; Frankum and Ogden, 2005). The smaller triangle arrows depict the 'height' or

‘depth’ of the blood sugar based on the number of times this was described and the adjective used (eg slightly high or really high).



**Figure 27 Visual representation of metaphors of movement/direction related to blood sugar**

The visual representation of the metaphors was an attempt to bring another dimension to understanding of the diabetes lived experience. Moser (2000) created a pictorial schema of the metaphor ‘success is a path’ and illustrated within this the passage of time and the different directions this path could take. She suggests that this visual representation of the metaphor allows for a more holistic understanding of the experience. In much the same way, the representation through Wordle™ (Figures 25 and 26) and the direction arrows (Figure 27) give an instant and easily recognisable illustration of the movement and direction aspect of blood sugar levels, in particular, and a sense of the volatility and sometimes random aspect of this, as described by the participants.

### 11.3.4 Study 2 The Language of Control

An analysis of the use of general metaphor led to further discourse analysis of the interview transcripts, specifically looking at the language of control. This was a theme that had appeared in the pre-prepared metaphors and was a significant part of the general discourse, but did not appear in the general use of metaphor. All uses of the word control were analysed and themed as summarised in Table 17.

Internal influences related to those aspects of managing diabetes that participants reported were within their own sphere of influence. Participants reflected that a key to controlling diabetes was acceptance of diabetes within their own lives. This then allowed participants to make a choice to take control (and not all participants made this choice) and find ways to achieve this. However they also acknowledged the difficulties of maintaining control. As Jill summarised:

*Diabetes is this constant balance and control, trying to maintain that constantly, and the reality is you're not going to be able to do that all the time. (Jill)*

Self belief and a sense of being self reliant were also critical to ability to manage. This was particularly important to Karen who made a point of trying to be prepared for every eventuality, planning medication and emergency supplies into an actual (and metaphorical) rucksack. For her this was about ensuring that other people did not need to take control:

*... in my head I should be able to control my diabetes, I don't need to be dependent on other people. (Karen)*

DISCOURSE OF CONTROL	
SUPERORDINATE THEMES	SUB THEMES
<b>INTERNAL INFLUENCES</b> Explanations given by participants about the process of control	<ul style="list-style-type: none"> <li>• Acceptance</li> <li>• Taking (or not taking) control</li> <li>• Achieving control</li> <li>• Levels of control</li> <li>• Self belief</li> </ul>
<b>EXTERNAL INFLUENCES</b> Circumstances outside the person's sphere of influence that impact on sense of control	<ul style="list-style-type: none"> <li>• Events, situations</li> <li>• Impact on level of control</li> </ul>
<b>DIABETES MANAGEMENT</b> Aspects of control specifically related to diabetes management	<ul style="list-style-type: none"> <li>• Preventing diabetes symptoms</li> <li>• Managing diabetes symptoms</li> <li>• Paradox of who's in control (person or diabetes)</li> </ul>
<b>WEIGHT CONTROL</b> A sub section of diabetes management and general weight management	<ul style="list-style-type: none"> <li>• As part of diabetes management</li> <li>• General weight control</li> </ul>

**Table 17 Discourse analysis of use of control**

External influences related to those aspects of control that participants considered to be outside of their sphere of influence. These included events and situations, which often occurred unexpectedly. Jessica reported that she had a very busy work schedule, which was often unpredictable, and she worked long hours. This took priority and it was only when work eased off that Jessica would consider other aspects of her life, such as diabetes:

*But certainly when I'm quieter at work I'm actually more in control of everything else.*  
 (Jessica)

Issues of control (Edwall et al, 2008; Handley et al, 2010) directly related to diabetes management included an attempt to control diabetes symptoms or to prevent diabetes symptoms developing (Gillies et al, 2007). Participants expressed anxiety that despite their best efforts, management was not straight forward and that control might be illusory. As Nancy explained:

*So in some way that process of having to be really regimented and in control kind of gave an illusion that you were in control but I know that there was always a kind of a*

*little underlying anxiety, even if I do this to the best of my ability it might not be good enough, it might not work. (Nancy)*

Many participants shared an image of diabetes being something separate from them, with its own driving force, often working against them. Susan had previously explored this in her metaphor of the tug of war. Many participants found it hard to work out whether they or the diabetes was in control. This paradox was succinctly summarised by Frances:

*.....does it [diabetes] control you or do you control it, by being in control you might have to do more, which feels like it's in control, but actually you are choosing to be the one who does the acting on yourself, as opposed to it acting on you without you having any control. (Frances)*

The final aspect of control related to specific issues around managing weight as a way to manage diabetes. Susan reported a complicated problem around food and diabetes and ways to control this. She described a struggle with body image and bulimia (Elliot, 2012), bingeing (Goebel-Fabbri, 2008) on sugar in particular, then worrying about the possible risk of complications and purging in an attempt to prevent this (Mannucci et al, 2005). Eating was a way of controlling stress but caused its own stresses. In an attempt to control her eating, Susan turned to sport:

*I think I got into sport more about weight control because I think that the eating difficulties, although I think it stems from diabetes, it became about my body image. (Susan)*

Similarly Martin reported eating to control his stress and to reward himself, but started to think that his attitude to food had become “*unhealthy*”. He stated that food had become his “*downfall*” and was convinced that it had led to his

diagnosis of pre-diabetes.

Helen described the difficulties of controlling food intake as part of her lifestyle change to prevent developing type 2 diabetes. Part of this was educating her family of reasonable portion sizes:

*And the only way I could control them, because I kept saying 'don't give me so much, don't give me so much' was to give them a smaller plate and then they got it better.*  
(Helen)

Handley et al (2010) suggested that people with diabetes needed to integrate or accept their diabetes to be in control. The findings certainly suggested many levels to the issue of control. Participants revealed that not only was acceptance of diabetes important but also crucial was their own self-belief as to how much they could control their diabetes. Even despite the participants' best efforts, good management was difficult to achieve and might even be illusory. Events and situations outside of the person's sphere of influence also impacted on this sense of control. The paradox of control, as described by Frances, was also interesting in that having to "*do more*" appeared like the diabetes was in control, but the very act of doing more meant that the person was taking charge. Susan saw the whole issue of control in diabetes as something that had no winners or losers. Instead she advocated an acceptance that control was never going to be perfect and that it was variable over time.



### **11.3.5 Study 2 Summary of Use of Metaphor to Describe Experience of Diabetes**

In summary, the pre-prepared metaphors indicated what was important to individual participants in terms of conceptualising their diabetes. For some this was about a long one-way journey, for others a struggle to achieve balance and control, or to make the 'right' choices. The metaphors enabled participants to reflect on their experiences, to find new meanings and to gain deeper insight. However it also highlighted, particularly in respect of Karen, that not everyone finds metaphors either useful or meaningful. This is further discussed in Chapter 13.

The metaphor analysis of all the interview transcripts revealed the range of metaphors used in everyday language and the main groupings displayed further insight into the ways in which participants explained their experiences. The prevalence of metaphors of movement/direction, in particular, enabled understanding of the constant action taking place on a daily basis to manage diabetes as well as the more long term aspects of progress, in terms of the journey. In addition the discourse analysis of concepts such as control brought awareness of the various facets of taking charge. For most participants this was very important, although not always straightforward, but it also revealed that for some, taking control of diabetes was not a priority.

## **11.4 Study 2 Occupational Therapy**

The second major aspect of this study was to investigate participants' views on the potential role of occupational therapy in the management of diabetes. Participants were asked to talk about how they used their occupational therapy skills (Creek, 2003) in their own diabetes self management, and how occupational therapy might be applied to diabetes self management in general. There was not general agreement and thus the data was also examined for barriers to an occupational therapy approach. In addition, as indicated at the beginning of the section on metaphors used within the discourse of the interviews (p.221) further analysis was applied to investigate the metaphors used to describe occupational therapy.

The four main themes of the occupational therapy analysis are summarised below:

- Applying occupational therapy to participants' own experience of diabetes
- Applying occupational therapy in general to diabetes management
- Possible integration of occupational therapy into diabetes healthcare teams
- Barriers to occupational therapy practice in diabetes management

### **11.4.1 Study 2 Applying Occupational Therapy to Personal Experience of Diabetes**

Participants varied in the degree to which they felt they applied occupational therapy practice or beliefs to their own situation. This is summarised into three

areas of occupational therapy role; awareness of occupational therapy principles; and applying those principles to own diabetes management. Table 18 summarises these areas and representation among participants.

APPLYING OT TO PERSONAL EXPERIENCE OF DIABETES			
SUPER-ORDINATE	SUB THEMES	EXPLANATION	Participants
OT ROLE	No role	Where participants felt that diabetes did not affect occupational performance and thus there was no role for OT in their self management	Frances, Karen, Jessica
	Uncertain role	Where participants felt that there probably was a role but did not know what this was	Helen
	Potential role	Where participants talked about how they could hypothetically have applied OT to their diabetes self management	Carol, Martin, Vanessa
	Specific role	Clear belief in OT role to the occupation of diabetes self management	Jill, Susan, Nancy
AWARENESS OF OT	Integration into thinking	Assimilation of OT principles / learning on thinking about health generally	Carol, Jill, Frances, Martin, Helen
	Impact on behaviour	Impact of OT principles / learning on health behaviour generally	Susan, Nancy
APPLYING OT	Specific aspects	Specific examples of how OT applied to diabetes self management	Jill, Susan, Nancy

**Table 18 Applying occupational therapy to personal experience of diabetes**

#### **11.4.1.1 Study 2 Occupational Therapy Role**

Three of the ten participants were definite that they could not see a role for occupational therapy in their own situation. For Frances and Karen this was due to overall management not impacting on occupational performance while for Jessica, ignoring her diabetes meant that she perceived that it was not affecting her lifestyle. One participant, Helen admitted to an uncertain role. She explained generally that she thought there was a role but was not clear what this could be. Carol, Vanessa and Martin did not apply occupational therapy

specifically to themselves but were able to describe what they could have done in terms of goal setting and looking at lifestyle issues. Jill, Susan and Nancy had a clear view of the occupational therapy role based on occupational therapy conceptual models and a belief in the value of occupation for health and wellbeing.

#### **11.4.1.2 Study 2 Awareness of Occupational Therapy**

Awareness of occupational therapy was integrated more readily into assimilating general health principles rather than specifically towards diabetes. Participants described that as occupational therapists they were more aware of health issues. These included aspects of risk management, complications, impact of stress, occupational balance and lifestyle issues.

Although aware of how aspects of occupational therapy could help manage health and wellbeing, only half of the participants put this into practice. For the majority this was related to a perception that they did not see the need to make changes to current lifestyles. Those who had made changes discussed ways in which they had used the principles of occupational balance (Matuska and Christiansen, 2008) and changing routines for better health and wellbeing generally.

#### **11.4.1.3 Study 2 Applying Occupational Therapy to Diabetes Self Management**

Three participants gave specific examples of how they had applied occupational therapy to their own diabetes self management. Susan described how fundamentally learning about the importance of occupation (Wilcock, 2006) and putting this into practice for health and wellbeing had enabled her to manage and accept her diabetes. Jill explained that she had used aspects of cognitive behavioural therapy (Duncan, 2003) learned in her training and had applied the Model of Human Occupation (Kielhofner, 2008) to understanding her own relationship with diabetes. Nancy described the occupation of her gestational diabetes and talked about her changed routines, habits and roles. She described how lifestyle choices were affected by and affected diabetes and discussed how she worked on lifestyle balance and self care.

#### **11.4.2 Study 2 Applying Occupational Therapy in General to Diabetes Management**

Participants were asked how they thought occupational therapy could be applied to diabetes management in others. Four participants were certain about occupational therapy's unique perspective while others were less convinced that it could offer anything different from other healthcare professionals. These latter views are explored in the section on barriers to occupational therapy practice.

Four participants had a clear idea of the role of occupational therapy and cited views on the value of occupation, were familiar with conceptual models of practice and espoused the "contemporary paradigm" of the centrality of

occupation to health and wellbeing, the recognition of the occupational nature of people and occupational problems or challenges as the focus of practice (Kielhofner, 2009 p.49):

*The lens that we come at with is OK this is lifestyle management, how is it impacting their occupations, what new occupations do you need to develop in order to support managing this chronic condition in a positive way, in a way that you still feel healthy, that you feel good and that it supports your occupational identity. (Nancy)*

*So I think OTs can help by just really analysing the person's day to day activities and figuring out with them why is that a barrier..... So it's just really about getting the individual to sit down and think 'OK so I do this so when can I do my injection' rather than thinking 'Oh I can't do it, I'm just going to ignore it' which is often what people do. And it's just brainstorming together..... So the skills of the OT would be the kind of goal setting and problem solving, the activity analysis, encouragement to do sports, the lifestyle kind of things, trying to think of the core OT skills. (Susan)*

*It's about placing occupational therapy there and saying 'actually, yeah, this isn't the end', we can have a look at that engagement in occupation to a healthy lifestyle, and it will be different for everybody, but it's about making that sort of positive link and in the context of that person's life and physical and social environment or whatever. (Vanessa)*

*I think given the nature of the beast and how it impacts on people's confidence and feelings and behaviour and activities that they do, what they feel they can't do, the beliefs about themselves, I think there's a massive role for OTs. (Jill)*

While strengthening the links between the profession's philosophy, theory and practice is seen as one way of building a greater understanding of the occupational therapy role (Creek and Ormston, 1996; Ikiugu, 2010; Kinn and Aas, 2009), Gustafsson et al (2014) point out that not all practice is consistent with the contemporary paradigm and suggest that all evidence based practice is viewed through this lens.

Discussion of the scope of occupational therapy practice revealed differences among participants as to its application. These differences reflected, to a certain extent, the practice areas that participants had worked in and the language used to describe occupational therapy. Aspects of occupational therapy highlighted by participants as applied to general diabetes management are summarised in Table 19. While participants were clear on how occupational therapy could be applied hypothetically, it was recognised that this would be harder to put into practice. Consideration of this was analysed in terms of how occupational therapy could ‘fit’ into diabetes teams, and the potential barriers that occupational therapy faced in applying practice to diabetes management. The following two sections address these areas.

Areas of Occupational Therapy Practice	Reference
Analysing activities of daily living	(Foster and Pratt, 2002)
Anxiety management	(Keable, 1989)
Balancing life priorities against managing blood sugar levels	Balance - (Matuska and Christiansen, 2008)
Baseline assessments	(COT, 2013; Laver-Fawcett, 2007)
Education	(Hoffman, 2010)
Education plus (how to apply advice to context of someone’s individual life)	(Packer, 2013)
Equipment advice	(Pain and Pengelly, 2010)
Goal setting	(Park, 2011)
Grading	(Hagedorn, 1997)
Holistic nature of practice (combining both physical and psychosocial aspects of practice, understanding the ‘whole person’)	(Sumsion, 2010)
Life management – understanding and supporting	(O’Toole et al, 2013)
Lifestyle change	(Clark et al, 2004)
Occupational role - intervening where complications of diabetes affect role	Role – (Kielhofner, 2008)
Problem and barriers identification	(COT, 2013; Duncan, 2009)
Psychological support	(McKenna, 2010)
Risk management	(Atwal et al, 2012)
Sustaining change	(Drake, 2013)
Work rehabilitation	(Cook and Lukersmith, 2010)

**Table 19 Scope of occupational therapy practice as applied to diabetes**

### **11.4.3 Study 2 Integration of Occupational Therapy into Diabetes Healthcare Teams**

It was clear from discussion in the interviews that it would be important for the occupational therapy profession to find some way of integrating practice into existing diabetes services rather than looking at occupational therapy as a standalone service. The themes generated by the data included consideration of the unique selling point of occupational therapy; how occupational therapy practice could support other healthcare professional team members; the ways in which occupational therapy could address perceived gaps in services; and practical ideas for disseminating these messages. These are summarised in Table 20. Consideration of these aspects of practice will be discussed further in Chapter 13 Theoretical Discussion.



POSSIBLE INTEGRATION OF OT INTO DIABETES HEALTHCARE TEAMS	
SUPERORDINATE THEME	SUB THEMES
<b>UNIQUE SELLING POINT</b> <i>what does OT do differently from the rest of the team – as cited by participants</i>	<ul style="list-style-type: none"> <li>• Context of / integration into lifestyle</li> <li>• Impact of environment</li> <li>• Empowerment</li> <li>• Work/life balance</li> <li>• Understanding of psychosocial aspects</li> <li>• Occupational exploration</li> <li>• Participation in life</li> <li>• Goal setting</li> <li>• Holistic</li> <li>• Recognition of individual approach</li> </ul>
<b>SUPPORT FOR TEAM MEMBERS</b> <i>not duplicating services, not stepping on toes, intervening to support what is currently on offer</i>	<ul style="list-style-type: none"> <li>• Understanding of rehabilitation</li> <li>• Bringing insight / getting on side</li> <li>• How to do as opposed to what to do</li> </ul>
<b>GAPS IN SERVICES</b> <i>what participants said they need/want which is currently not on offer but which could be filled by OT</i>	<ul style="list-style-type: none"> <li>• Understanding why self management is difficult</li> <li>• Psychosocial elements</li> <li>• Process of change</li> <li>• Not being judgemental / giving choices</li> </ul>
<b>HOW TO ACHIEVE INTEGRATION</b> <i>how can OT show its place in the team</i>	<ul style="list-style-type: none"> <li>• Being clear about OT role</li> <li>• Communication of OT role</li> <li>• Doing something different (USP)</li> <li>• Information sheets</li> <li>• Outcome measures understood by team</li> <li>• Education of students as change agents</li> </ul>

Table 20 Suggestion as to the possible integration of occupational therapy into diabetes teams

#### 11.4.4 Study 2 Barriers to Occupational Therapy Practice in Relation to Diabetes

For two thirds of the participants, potential uncertainty about core beliefs and values led to debate in the interviews as to whether occupational therapy had a role at all in diabetes self management. Table 21 summarises the views of the participants on the barriers to occupational therapy practice in relation to diabetes in terms of the current health service; the medicalisation of diabetes; issues within the professional generally; and lack of current evidence for

occupational therapy in diabetes self management specifically. As Frances suggested:

*I'm sure there's a large percentage of the OT population that are probably not even aware that there is a role that could be, or a need that could be met probably ..... so we probably need the evidence, don't we, to suggest that we can have some impact or some part or some role to play in it. (Frances)*

BARRIERS TO OT PRACTICE IN RELATION TO DIABETES	
SUPERORDINATE	SUB THEMES
Health Service	<ul style="list-style-type: none"> <li>• Development of services without OT</li> <li>• OT not in established pathways</li> <li>• Difficulty of commissioning of new OT services</li> <li>• Lack of recognition of scope of OT practice by others</li> <li>• Expectations of OT by other health professionals</li> <li>• Other professionals taking on OT roles</li> <li>• Outcomes required for credibility</li> <li>• Restrictions on current OT practice</li> </ul>
Diabetes	<ul style="list-style-type: none"> <li>• Medicalisation of diabetes</li> <li>• Complexity of condition</li> </ul>
OT Profession generally	<ul style="list-style-type: none"> <li>• Lack of general evidence base</li> <li>• Belief in ourselves as profession</li> <li>• Difficulty communicating role to others</li> <li>• Inability to take professional stand re roles</li> <li>• Recognising scope of own practice</li> <li>• Differing abilities</li> <li>• Limiting OT role</li> <li>• Underground practice</li> <li>• Theory / practice divide</li> <li>• Educating next generation of OTs</li> <li>• Lack of OT specialists</li> </ul>
OT Role in diabetes	<ul style="list-style-type: none"> <li>• Neglected / under utilised</li> <li>• Lack of specific evidence base</li> <li>• Uncertainty as to role in diabetes</li> <li>• Devising therapy intervention (who, when, how, what)</li> <li>• How to cost up and break in to existing services</li> </ul>

**Table 21 Perceived barriers to occupational therapy practice in relation to diabetes**

These occupational therapy barriers are discussed in terms of understanding of the role of occupational therapy, scope of practice and language used.

#### 11.4.4.1 Study 2 Understanding of Role of Occupational Therapy

Three participants were less convinced that occupational therapy could offer anything different from other healthcare professionals. As these three participants reported:

*I don't think it has to be an OT, you see, I think anybody who has the skills to talk about putting diabetes in the right place in your life, getting it integrated. (Frances)*

*I'm not 100% sure if there is a role or not. I suppose I'm not sure whether it's a diabetic nurse role or an OT role but I can imagine where function is affected that may be but I'm not 100% clear how it would work exactly. (Karen)*

*I can see a role but I'd take a bit of convincing still that OTs would be any better than somebody else, but I'm not sure why. (Jessica)*

Although these participants were able to identify potential areas of practice for occupational therapy, this focussed more on the narrow perspective of intervening once later diabetes complications impacted on daily lives:

*Where I see a role for an OT is when the effects of diabetes have affected somebody's occupational performance. So somebody who's beginning to lose the sensation in their feet and their mobility goes, or in their hands, or in their sight or whatever .... (Frances)*

This is similar to the approach to diabetes taken in the 1970s and '80s, where the focus was on practical occupational therapy solutions to later complications of diabetes (Andrew, 1987; Budurowich and Lofton, 1979). More recently, Hwang et al (2009) identified that blood sugar and cholesterol control, foot care, and pain and fatigue management were the main areas of concern to older adults with diabetes. This appears to reflect the bio-medical response rather than a wider health promotion based on occupation. Scriven and Atwal (2004, p.426) refer to this as a traditional “downstream secondary or tertiary health promotion

role” rather than an earlier holistic focus on “upstream” health promotion and engagement in occupation for health and wellbeing. Scriven and Atwal (2004) suggest that this upstream focus would widen the mandate and remit for occupational therapy but that there is little evidence of this happening in practice. Similarly Aguilar et al (2013), who looked at the ways in which professional values of Australian occupational therapists were linked to core beliefs, found that there was no consensus as to involvement in health promotion being an essential value.

In terms of understanding the role of occupational therapy, Wilding and Whiteford (2009) suggest that practitioners should be connected to the philosophical foundations of the profession to meet its ethical and moral obligations. For some of the participants, many years from training and with practice reduced by the work setting, it was difficult to make that connection. As participants stated:

*It's like when the students come and they ask me what sort of model of practice it is and I say I have no idea what a model of practice is. (Jessica)*

*Well I just think it hasn't affected me in my occupational performance so therefore if you were being strict as an OT in terms of what our key roles are I, for myself, would not have seen a role for an OT. (Frances)*

It can be argued that the paradigm shifts of the profession, even in the last 20 years (covering the average occupational therapy working life of the participants) may have contributed to some of this uncertainty as to the role of occupational therapy. Clouston and Whitcombe (2008) suggest that core skills may be

redefined pragmatically by work settings and government drivers, while Wilding (2011, p.293) argues that occupational therapists can be “*unconsciously complicit*” with the prevailing work discourses and “*unwittingly*” contributing to the narrower focus of practice. Wilding and Whiteford (2007) and Molineux and Baptiste (2011) suggest that this is particularly prevalent in a biomedical setting, especially where the efficacy of practice based on occupation-based discourse is undermined by other professionals (Ashby et al, 2015).

#### **11.4.4.2 Study 2 Scope of Practice**

Understanding of the occupational therapy role is closely linked to the scope of practice. The sense of appreciation of having ‘any’ role in the health service was strong. As Jill stated:

*I think as a profession, for whatever reason, we have always I think felt ourselves on the back foot. We’ve always allowed ourselves to be shoved into the sheds at the back of a prefab and been grateful. (Jill)*

In addition there was concern that occupational therapy scope of practice within diabetes could be constrained by a perspective, perhaps shaped by past work experiences and expectations:

*I don’t think telling people, educating and giving them rules and instructions is going to work. And that wouldn’t have helped me at all. So I think OTs often, I think OT is weak if all it does is refer to an educational frame of reference and think what people need is educating and teaching and telling what to do. There’s enough people out there doing it already. (Vanessa)*

Clouston and Whitcombe (2008) argue that the scope of occupational therapy practice can be undermined by views of the profession from other healthcare

practitioners, particularly those who are in a more powerful position in the health hierarchy. Cooper (2012, p.205) suggests that, in Canada at least, scope of practice has been narrowly defined by others as moving from *“ladies with pink bunnies”* to *“people with the grab bars and the raised toilet seats”* with the potential for lost opportunities (Wilding, 2011). Research by Kinn and Aas (2009, p.116) revealed the role of occupational therapists seen by other members of the multi-disciplinary team as *“the knitting lady”*, the *“kitchen-training lady”* and *“the technical-aid expert”*. Even within the profession, occupational therapists have described themselves as *“jack of all trades”* or as a *“chameleon”*, who blends in to the practice area as a *“gap filler”* (Fortune, 2000, p.228). By not having a clear picture ourselves of the scope of practice then it is likely that the general public, as well as other professions, will struggle to understand the role of occupational therapy (Dickinson, 2003; Turpin et al, 2012). Hughes (2001) argues that if we are not sure of our own practice then this is hardly surprising because it has neither a statutory role nor inherent expectations.

Vanessa is clear, however, that occupational therapists need to move beyond what others expect:

*It's about placing occupational therapy there and saying 'actually, yeah, this isn't the end', we can have a look at that engagement in occupation to a healthy lifestyle, and it will be different for everybody, but it's about making that sort of positive link and in the context of that person's life and physical and social environment... (Vanessa)*

#### **11.4.4.3 Study 2 Language**

It has been argued that the language occupational therapists use contributes to uncertainty about professional identity, role and scope of practice (Creek 1998). Denshire and Mullavey-O'Byrne (2003, p.254) argue that a focus on "*techno-rational*" terms by occupational therapists to describe practice can lead to the "*artistry*" of practice remaining hidden. Cooper (2012) suggests that our focus on professional language is also at the detriment of understanding by the public.

Some participants, working within the hospital environment, referred to 'function' rather than 'occupation' which potentially limited their understanding of the role as being reduced to 'only when function is affected by diabetes'. Even those who used the terms 'occupational role' and 'occupational performance' had restricted the scope of practice to Scriven and Atwal's (2004) 'secondary' engagement once diabetes had had an impact. Recent articles on occupational therapy and diabetes also reflect this focus on function, most notably Ratzon et al (2010) whose research concerned hand function and whose title was 'identifying predictors of function in people with diabetes'.

Denshire and Mullavey-O'Byrne (2003) argue it may not be the use of language per se that distinguishes occupational therapy as a profession, but the therapists' clinical reasoning. Nancy, however, recognised the need to be upfront about language and terminology in order to explain occupational therapy's role to both clients and other professionals:

*Nursing terms it chronic disease management and I think as OTs we haven't picked up on that language as much .....My experience living with it even for that short amount of time is realising it's such an important thing and so lifestyle choices, habits that people make, the support you have in the environment, all those things that we look at from OT perspective are just as important especially because we know the serious secondary consequences that will happen if people aren't managing their diabetes well, or even when they are. (Nancy)*

#### **11.4.4.4 Study 2 Summary of the Barriers of Occupational Therapy Practice in Relation to Diabetes**

The issues described above in terms of understanding of the role of occupational therapy, the language and scope of practice all add up to considerable barriers in widening the profession's role into all aspects of diabetes self-management.

Wood et al (2013) found the barriers to occupational therapists working in health promotion related to lack of funding and preparation as well as the limited understanding of the occupational therapy role. They talk about the role of occupational therapy in this area as “*largely unrecognised*” both within and outside the profession. They suggest that part of this reason is the alignment with the biomedical model which may have caused therapists to lose sight of the occupational nature of occupational therapy's view of health (Molineux and Baptiste, 2011).

For the participants, barriers to occupational therapy practice in relation to diabetes included many of the issues raised above in terms of lack of recognition of the scope of the role by others, plus the expectations that other professionals



had of occupational therapy. The difficulty of breaking into existing diabetes care pathways was also seen as problematic, due in part to the medicalisation of diabetes and a general lack of evidence base. As Vanessa and Jill explained:

*I don't think most of your OTs on the street, when diabetes is one of a list of things, is going to focus on that and think 'oh well I should talk to you about your exercise or let's find out what you're doing'. I think it's just like another thing, because we kind of medicalise it, it's medical, it's somebody else's deal. We don't think of it as occupational I think. (Vanessa)*

*If we don't believe in ourselves we're not going to get managers believing in ourselves, to believe in us.....I think we constantly sort of limit ourselves in terms of what we believe other people expect us to do, particularly on the wards. (Jill)*

Nancy recognised the importance of trying to overcome those barriers on a number of different levels from advocacy for the person with diabetes to showing wider examples of how occupational therapy could make a difference:

*If you can get other team members to recognise the value of what you are contributing to the team that's incredible. It's not just this box, this is all they do. So I think it's many different kinds of approaches. From a macro level, figure advocacy, figure working at care systems down to if I work in this agency do people understand that I have an expertise that can be contributed to people living with diabetes..... And how to make it really clear what the unique part is that we can do.....you're facing a chronic condition, how can you redesign your occupations to fit the needs of that chronic condition as well as maintaining the occupations that have always been important to you or that are important. (Nancy)*

Pyatak (2011b) highlighted similar themes to Nancy, in her research on young adults with type 1 diabetes, examining how engagement in occupation influenced their ability to manage diabetes and how their self-management strategies shaped occupational participation. More recently Fritz (2014) and Thompson

(2014) have started to examine the influence of habits and daily routines on diabetes self management.

However it is significant that views about potential barriers were prevalent across all participants and, even for those who were convinced of occupational therapy's role and the importance of integrating into existing services (above), the practical ways in which the profession could actually do this appeared daunting:

*I can see it intellectually, I can argue it, but I am stuck at the pragmatics and the policy for you. (Vanessa)*

Concerns expressed by participants about the occupational therapy profession and its ability to 'break into' existing services led to a deeper exploration of the language used through further metaphor analysis (Cameron and Maslen, 2010). This is summarised below.

#### **11.4.5 Study 2 Metaphor Analysis of Occupational Therapy**

All instances of metaphors used to describe occupational therapy across all participants were identified and applied to vehicle groups. This included occupational therapy in general, how it might be applied to diabetes management, the impact that occupational therapy had had on them personally. As can be seen in Table 22, the main vehicle groups were building/ construction (n=21); movement/direction (n=15); machines/tools (n=14). These are also summarised below:

Occupational Therapy		
Vehicle Group	No of instances	Participants
Building / construction	21	Frances, Jill, Susan, Vanessa, Helen, Nancy
Connection	1	Nancy
Container	11	Frances, Jill, Susan, Vanessa, Helen, Nancy
Food / cooking	3	Jill, Susan, Nancy
Forces	12	Martin, Jill, Susan, Vanessa, Helen, Nancy
Games / sport	3	Jill, Vanessa
Machines / tools	14	Frances, Martin, Jill, Nancy
Military	4	Jill, Vanessa, Nancy
Movement / direction	15	Carol, Frances, Martin, Jill, Susan, Helen, Nancy
Nature	2	Vanessa, Nancy
Religion	1	Nancy
Resources	6	Frances, Jill, Susan, Nancy
Warning	1	Susan
TOTAL	94	

**Table 22 Details of metaphor vehicle groups used to describe occupational therapy**

Building construction (n=21) metaphors referred to:

- Occupational therapy frameworks and frames of mind
- Doors – occupational therapy being behind closed doors, not getting a foot in the door
- Keys – finding key moments, beliefs and practice being key
- Underground – occupational therapy practice being out of sight

Movement /direction metaphors (n=15) referred to:

- Navigating healthcare systems, occupational therapy profession moving forward (or back)
- Pathways – importance of occupational therapy defining, being on or not fitting into
- Narrative slope (in MOHO assessment (Kielhofner et al, 2004))

Machines / tools (n=14) metaphors referred to:

- Scope of practice, cycles of theory/practice
- Using OT models as a lens to view practice
- Tools – giving people tools to enable change, theory tools to improve practice

The metaphors of occupational therapy practising behind closed doors and being an underground practice were stark with participants acknowledging the difficulties of delivering an occupation focussed practice when perceived expectation was to fill gaps in services or take on discharge roles. In this way the scope of practice in terms of enabling engagement in occupation for health and wellbeing was seen as something that had to be hidden from employers rather than promoted:

*I think sometimes people believe that but they sort of do it [OT practice] a bit behind the back door so they're keeping up a kind of medically front even if they're operating slightly more occupationally focussed. (Vanessa)*

*..because I think that's a lot of why it's stayed underground because they get out in practice and the forces say 'well you can't bill for that or you can't do that' and they go 'OK' but they keep doing it (laughs). A lot of it's about trying to help therapists find their voice ..... as they navigate that underground practice, it's like they know that's the case but this pressure's so strong that it's easier just to keep it underground. (Nancy)*

Fleming and Mattingly (1994) raised the issue of underground practice in the USA many years ago, suggesting that this was due to the conflict between occupational values and the biomedical culture. They reported the difficulty for

occupational therapists of restricting practice along biomedical lines while wanting to treat the whole person. As the latter was not reimbursable, it was not documented and thus became “*underground practice*” (Fleming and Mattingly, 1994, p.296). It is interesting that, within the NHS, even without direct billing, participants reported a similar situation of keeping the holistic occupational therapy practice hidden.

#### **11.4.6 Study 2 Summary of Role of Occupational Therapy in the Management of Diabetes**

This study revealed debate around understanding of occupational therapy, scope of practice, the language of the profession and how these can result in perceived barriers to applying occupational therapy to diabetes self management. In addition it demonstrated powerful stories of how participants applied occupational therapy to themselves and how occupational therapy could have a wider role with this long term condition. In summary the findings suggest the complexity of applying occupational therapy to an area of healthcare where it is not already established. Although some participants had applied occupational therapy practice to their own situation or were able to theoretically discuss how they might have done so (if applicable), being able to define how occupational therapy practice might be applied in general was more difficult. Perceived barriers are many and varied and the strength of these views, particularly in terms of restricted occupational therapy practice, is reflected in the metaphors used. It is acknowledged that the findings represent the views of the ten participants and may not be representative of the profession as a whole.

## 11.5 Study 2 Summary

This chapter has described the findings of Study 2 in terms of metaphor and the potential role of occupational therapy in diabetes self-management and discussed these in relation to the literature. The findings indicate that metaphor is a useful tool for understanding experiences of diabetes and that its use is also valued by participants to enhance their own knowledge of this condition. The examination of the role of occupational therapy raised many questions for participants in terms of understanding, scope of practice, professional language and barriers to fitting into and complementing existing services. Nonetheless some participants saw a very clear role based on the contemporary occupational paradigm and a proposed framework for occupational therapy practice will be considered in Chapter 13 Theoretical Discussion. The next chapter reports the findings of Study 3. The following reflection considers the researcher role in attempting to recreate the lifestyle changes that participants make and the impact this might have on the study.

### *Reflections on 'walking the talk':*

*I wanted to see what it was like to do the things that are expected of people with diabetes. How easy or difficult is it to make changes to diet and exercise. I persuaded Sandy to take on a bit of 'action research' with me. Apart from doing the 5:2, we are both thinking about food differently, making healthier choices, drinking less alcohol (sometimes) and more water. But I also wonder how sustainable this is. How long can we do this, can we say no to temptations that ultimately will not do us good, not feeling we have to finish the plate of food in front of us, overturning cultural or friendship norms that might be causing us to overeat or over drink. The question then is whether my own narrative affects the study. As time goes on and I become more immersed does this change my views and the direction of the study? For sure the complexities are becoming so much more evident. (June 2013)*



**Figure 28** Grappling with the data

*I photoshopped images of me and stitched them onto material, along with panels of organza, scraps of paper and pieces of tissue paper. I then stitched them all onto kitchen towel. The 4 pieces of kitchen towel were then sewn together and I applied some ribbon borders. The end result is something which looks a bit like a quilt, the colours are bold and work well, the design isn't entirely 'right' (some of the pieces aren't in the order I had anticipated). In each panel there is a me and a shadow me grappling with the data, represented by little scraps of paper and random machine embroidery stitching, representing the different ways I approached the data and showing that the data could be slippery and hard to interpret at times. The organza represents hidden depths. Overall it is another reflection on attempting to ensure that the voices of the participants are heard and that my analysis represents all the different voices.*

## **12. Study 3 Findings and Discussion**

### **12.1 Chapter Outline**

This chapter describes the findings of Study 3: Diabetes in relation to the potential occupational therapy role. Theoretical consideration of these findings in relation to study 1 and study 2 will be examined further in Chapter 13. As in Chapter 11, this chapter will be organised with the discussion integrated with the findings in each section. After the introduction, the prepared metaphors and metaphors used in general discourse will be identified and discussed. This will be followed by shared themes across the participants as to the main issues identified about living with diabetes, and participants' ideas about potential solutions to their concerns. These potential solutions will then be considered from an occupational therapy perspective. All tables and figures in Study 3 are coloured pink to differentiate them from tables in the other two studies.

### **12.2 Study 3 Introduction and Participants**

This third study considered whether people (non-occupational therapists) would find metaphors useful to describe their experiences of diabetes. The focus of this study was also on experiences of diabetes support, perceived gaps in services and potential solutions to ascertain whether these could be matched by the values, beliefs and skills of occupational therapy practice. This section describes the participants. Pseudonyms are used for each participant.



### 12.2.1 Study 3 Participants

Five participants all with a diagnosis of type 2 diabetes were recruited to the study. Table 23 shows the demographic details of the participants. At the time of the interview all were in employment and reported a range of work and diabetes experience.

Pseudonym	Time since diagnosis	Age	Work role
Frank	10 years	59	Mindfulness practitioner
Josephine	4 years	67	Sales and promotion
Louise	15 years	66	Company Director
Margaret	6 months	64	Private carer
Marilyn	5 months	34	University administrator

**Table 23** Demographics of Study 3 participants

Frank had had diabetes for 10 years and reported that he was still trying to find causal links between activity, mood and blood sugar levels. He commented that his diabetes was very variable and at times he did not feel that he understood the mechanisms of why it was sometimes better managed than at other times. By contrast Josephine, who had had diabetes for four years, reported that her diabetes had little impact on her lifestyle and that most of the time she was unaware of it.

Louise had had diabetes for 15 years and described her sense of exclusion when she was diagnosed. This was related to both shopping for food and in food choices she was able to make when going out with friends. She reported that her diabetes had had a significant impact on life in general and that sometimes she felt like a “*social pariah*”. Margaret was newly diagnosed with diabetes and was able to share her experiences of initial diabetes education and interactions with health services. Margaret described a number of other family health conditions

and life events which impacted on her attitude to her diabetes diagnosis and her need to take early control. Marilyn had also been recently diagnosed and reported that she was struggling to come to terms with the diagnosis and the life choices she would have to make. In addition the diagnosis had challenged her fundamental beliefs about nature and religion and had also tapped into memories of a relative's experiences of diabetes.

## 12.3 Study 3 Metaphor Preparation, Usefulness and Analysis

### 12.3.1 Study 3 Prepared Metaphors

This section describes the metaphors that study 3 participants prepared prior to the interviews, the themes related to generating the metaphor and the usefulness of metaphors to understand diabetes. All participants described their metaphors and none prepared pictures. Table 24 summarises the range of metaphors.

Pseudonym	Metaphor
Frank	Kayak journey
Josephine	Shadow
Louise	Faceless enemy
Margaret	*Floundering on the end of a line
Marilyn	Walking in the fog

**Table 24 The prepared metaphors of participants in Study 3**

The following brief excerpts, which are put together from various parts of the interviews, introduce and then explain the metaphors in the participants' own words.

Prior to the interview Frank had seen the researcher's sea metaphor (Study 1, p.186) and explained that this had resonated with him. Like Jill in Study 2 (although there had been no contact between participants), he had changed it to being a kayak journey. For Frank the metaphor was the journey and the kayak represented the management tools that were available to him. He reported that his journey was always different but that a certain amount of preparation could be factored in. Ten years on, he explained, the water could still change from calm to choppy:

*Well I really liked the metaphor that you showed me about the stormy sea. And I still think of that.... And I've changed it a bit to being more of a kayak journey. So in terms of my journey, I've changed my kayak ..... I think my control of my diabetes is in this faster kayak. And there are times when I'm paddling and it's all bliss and it's still and everything's perfect. And there's other times when I'm actually worried whether I will get back and that could be in the sea or it could be on a river. There's times when there's some rapids and I can think 'it's OK I've got the skill to get down this' and other times when I feel that I've got very little control and you just have to have the ability then to keep going because you know you'll be able to manage as long as you do all the stuff that you know how to do. (Frank)*

Josephine's metaphor reflected her feeling that her diabetes was very much in the background and not something that was in conscious thought very often. She described her diabetes as a shadow. The shadow cannot be seen until a light is shone on it, as in a healthcare appointment:

*I would say it's like a shadow because most of the time you don't see it but certainly if you put some light on it, there it is..... Because really I don't dwell on it at all..... It's not something that's a shadow hanging over me, or a black owl sitting on my shoulder. It's something that's completely invisible until somebody points it out. (Josephine)*

Louise chose to focus on one aspect of her diabetes for her metaphor of the faceless enemy. She explained this was related specifically to high fasting glucose in the morning which was an aspect of her diabetes which greatly concerned her:

*The one thing that really wears me down is high fasting glucose in the morning, even if it is low at bedtime. It doesn't actually matter how good you are, your liver works against you. All on its own. You feel as though the faceless enemy gets you in the night and totally skews your sugar level..... That's my real bête noire... [it's] very scary..... So I have become slightly neurotic about this one issue because I feel that if I could control that everything would totally change .... half the day I have a totally artificial, as it were, not food induced, glucose rise which is screwing my HbA<sub>1c</sub>.*  
(Louise)

Margaret did not prepare a metaphor beforehand for her experience but used the following metaphor in the interview to describe being 'hooked' in by the health service and then being left to fend for herself while waiting for the next appointment. \*In feedback from the report sent out to participants she stated she was happy with this representing her metaphor:

*It's a bit like throwing out a fishing line and you're on your own. They leave you, they let you flounder.* (Margaret)

Marilyn described her diabetes as like walking in fog. For her this summed up her confusion about what was the right thing to do, and what were the right things to eat (the obstacles). She explained that at this early stage it felt as though the fog extended a long way and that it was something that she needed to negotiate:

*It's really confusing, it is, it's a bit of a fog, a bit foggy and I kind of feel like there's obstacles in that fog, waiting for me, lampposts waiting for me to walk in to (laughs) .... It's so foggy so I feel it's so grey and you can tread carefully and tread slowly through it, following all the advice you've been given but, you know, the advice is conflicting so you kind of, I don't know, it feels like there are traps and if you don't tread absolutely perfectly you're going to end up with no legs (laughs), you'll end up*

*with no sight..... that fog's still going to be there and whether that clears because of meds or whether it clears because of action I take with my diet, I don't know but, maybe a bit of both. (Marilyn)*

Each participant's metaphor was individual reflecting their different experiences of diabetes but there were common themes across the interviews which are examined further below. The response to generating metaphors was mixed. Some participants reported spending time to find one that was a good 'fit'. Due to the many aspects of managing diabetes some participants wondered whether a number of different metaphors for each of those aspects would be more helpful than one overall metaphor and participants reported trying out a number of ideas. It was also clear from the participants that their metaphors could change from day to day and over time, depending what was particularly important or difficult at the time, reflecting the changing nature of living with a long term condition.

Participants reported that thinking about the metaphor was useful in terms of reviewing life with diabetes and what it meant to them and stated that generally this was not something they were asked to consider by health professionals:

*Yeah, 'cause it's got me to review my journey and, you know, with all the other distractions in life and all the things I've got to think about, the diabetes thing I've kind of just been living and you aren't asked to sit and think about how it felt and how, you know. Most people don't mention it to be honest..... Yeah so it was nice to be asked to reflect on that I think. (Marilyn)*

Caution was also expressed about not making assumptions about the meaning of metaphor and ensuring clarification. As Frank explained:

*You could look at three different people in three different kayaks, in exactly the same kayak in exactly the same river and they'll all be in a different place. (Frank)*

### **12.3.2 Study 3 Metaphors Used Within the Discourse of the Interviews**

As in Study 2, it became apparent when analysing the interview transcripts that metaphors were used frequently in the discourse. Using the template from study 2, based on Cameron and Maslen (2010), metaphors were identified and grouped into common source domains (Kosvecses, 2002). Table 25 gives examples of all metaphors used by all participants and their allocation into these source domain vehicle groups.

It can be seen that a range of metaphorical terms were used by participants to explain their diabetes experiences. Many of these are common to those found in Study 2 (see Table 14 in Chapter 11.3.2, p.222). The third column shows the overlaps between metaphors used by participants in Study 2. The metaphors used are put into context in Section 12.4 which reports the themes across the participants. Consideration of the general use of metaphors within all the interviews is discussed in Chapter 13 Theoretical Discussion.

VEHICLE GROUPING (source domain)	METAPHORS COLLECTED INTO GROUPING	OVERLAP WITH STUDY 2
ART & CRAFT	join dots, knitting, masking, pattern, picture, tailor, wool, wooliness	picture, woolly
BUILDING/ CONSTRUCTION (including materials)	door, (closed) (stable) door, edge, framework, key (door) (latch) key, keystone, line, load, rails, safety net, stacks, table, window	door, framework, key, line, rails, window
CONNECTION	fall in love, heartbroken, stayed together, relationship	relationship
CONTAINER	bag, (in) (outside) box, (off) chest, hat, (in) (outside) head, (enter) headspace, head set, (back of) mind, (in) shoes, (on) shoulders	(in) box, (in) (out of) head, headspace, (back of) mind
EDUCATION	n/a	
FOOD / COOKING	boils down, eggs, lump, menu, plates, swallow	consumes
FORCES	beat, blast, blown, blows, building up, bumping, buried, crack, crown, drag, dragging, drowning, grab, hammered, hit, jolt, knock(s), knocking, overwhelmed, pressure(s), pressurise, punched, pushing, ripples, shock(s) (ed), struck, surge	builds up, bump, drag, hit, knock back, pressure, pushing, shock (ed), struck
GAMES/SPORT	aim, ball, breakout, capsize, cards, hoops, jigsaw(s), juggle, jump, life raft, odds, pieces, pitch(ed)(ing), play, rucksack, running, slide, swing, tag, throwing, track, tumbling	ball, jump, pitch, running, track
MACHINES / TOOLS	button, crutch, figure, focus, gear, job, MOT, order, programme, pumping system, razor, scale, screw, spin setting, tick, ticking over, toolkit, tools, washing machine, wheel	crutch, focus, scale, ticking, tools
MILITARY	battle, bullet, conflict, discipline, fight(ing), firing, fought, killer, martyr(dom), minefield, punished, punishment, rear-guard action, rocket, shooting, struggle, struggling, tanking, tied up	battle, discipline, fight, fought, shoot, struggle,
MOVEMENT/ DIRECTION	along, away, back, backwards, below, deepening, dips, down, drop, dropped, dropping, fall, fell, flow, forwards, high(er), journey(s), lift, low(s), lowered, move, move on, narrow, pace, path, rise, rising, road, route, slip, straight, stride, tipping point, top, up, way	back, depth, down, drop, dropped, fall, forward, high (er), journey, low, moving, pace, path, route, slip, up
NATURE includes landscape, light/ dark, plants, animal	border(line), flea, grain, herd, rat, monster, symbiant being, sucker, turkey, wounded animal	borderline, beast, crop,
RELIGION	soul	devil
RESOURCES	band-aid, gold, pill, plaster,	resources
WARNING	n/a	

**Table 25 All metaphors used by all Study 3 participants and their groupings**

The findings reveal that the use of metaphor to describe experiences of diabetes resonated with these participants. Four of the five participants reported little difficulty in using metaphor to encapsulate their experience and commented on its usefulness to examine how they felt about their diabetes (Cameron, 2003; Czechmeister, 1994). This also reflected the work of Stuckey (2009) who focused on the ways in which creativity and metaphor could help participants to find meaning for their diabetes. Although her client group were people with type 1 diabetes, the experience of finding meaning in this way was shared by the participants in this study who all had type 2 diabetes. Participants commented that exploring how they felt about their diabetes was not something they were generally asked to do. Preparing metaphors before the interviews allowed what Gauntlett (2007, p.22) describes as an *“underground incubation”* whereby thinking through metaphor allows connections to be made and ideas linked together to give structure to how people think about the experience.

Although all the metaphors were different, there were some common themes. Of the four metaphors prepared prior to interview, two were ‘journey’ metaphors (Zaltman and Zaltman, 2008). Frank’s kayak journey metaphor also reflected other aspects of his life context (Stuckey, 2009). For Frank, in particular, the journey was a very variable one with periods of calm and times when the river was very turbulent but he was always moving forward. He saw his management of diabetes as being dependent upon the tools at his disposal which, in his metaphor, were represented by different types of kayak or paddles. Marilyn’s depiction of journeying through the fog conceptualised being at the



beginning of the journey and the difficulties of knowing which way to go and her fear of bumping into obstacles or falling into traps. This was similar to other diabetes metaphors of being without a destination or a map (Frank, 1995) or being stuck or immobile (Fullager and O'Brien, 2012; Mallinson et al, 1996). This suggests that careful exploration of journey metaphors are required to ascertain whether people are able to make forward progress or are struggling with new situations or periods of particular difficulty.

The other two prepared metaphors, Louise's faceless enemy which attacked her in the night and Josephine's shadow, both had elements of hidden, internal aspects of diabetes. Shiu and Wong (2002, p.158) describe the "*silent invader*" of diabetes of one of their participants and in another study there is a similar "*uninvited companion*" (Ingadottir and Halldorsdottir 2008, p.610). Josephine's shadow metaphor was an acknowledgement that her diabetes did not affect her on a daily basis and she was keen to point out that there was not anything sinister about this

*Initially I was thinking about it being something quite sort of stealthy but I couldn't get a metaphor that was appropriate because it's not like a snake, I don't feel it's, maybe I'm being cavalier, I don't think it's dangerous. Then I thought about a black panther or something like that and then that sort of led me onto dark thoughts and I thought 'ooh, what about a shadow'. It's a bit like that. (Josephine)*

This indicates again the need to explore people's particular metaphors with them so that assumptions are not made as to whether they are positive or negative images (Gauntlett, 2007). For Louise, her metaphor represented a very definite negative and unseen force that did battle with her, while Josephine's shadow was

more of a benign presence, only making itself felt when it was brought to light in the context of healthcare appointments.

Margaret, who did not prepare a metaphor prior to the interview, used two major metaphors in the discourse of the interview which gave an opportunity to explore these two issues that were particularly pertinent to her situation (Radley, 1995). The first of these, describing the feeling of being hooked into the health service and then left floundering appeared to show the gap between the rhetoric of self management support and actual clinical practice (The Health Foundation, 2011). For Margaret the reassurance that she required to know that she was doing the 'right thing' was missing. Margaret's other metaphor was "*too many things sitting on my shoulders*". She described feeling weighed down by the expectations of others, of family concerns, of health issues and her emotional response to all of these issues. As she explored this area it was almost possible to feel her resisting the weight of her words dragging her down and her struggle to rise up to take charge of her life.

The need to explore people's metaphors and allow for personal explanation was also highlighted by Frank, who expressed some caution about their use and the need to be clear about the context:

*The difficulty I think for a health professional talking to me is you don't actually know how I feel being here. I could have been round some major rapids just round a bend further up that you can't see and I'm now here paddling in something fairly steady thinking 'thank God for that'. Or I could be dreading what's coming next, having just experienced that, or I could just be thinking 'this is great, I'm really having a good time'. So I think it's difficult to see the context the person's in. (Frank)*

He explained that both the person's back story and the need to be present to what the person is saying is very important, and he was not sure whether all health professionals would have the skills to do this. Despite this caution, Frank reflected the experiences of the other participants when he explained:

*It is useful to be asked to do the metaphor bit. It's a way of you thinking about your experience and in my head, because partly because these are things I do, the idea of thinking about things as a journey is useful, whether that's someone thinking it's a journey on a motorway or someone thinking it's a journey into outer space or whatever, is irrelevant, it's what's your journey. (Frank)*

## 12.4 Study 3 Shared Themes Across Participants

Interview data, including the metaphors, were analysed individually and then across participants. The main themes around diabetes self-management are summarised alphabetically in Table 26 along with relevance to participants. Five of the ten themes were pertinent to all of the participants. A description of each of these themes is given below and discussed in relation to the literature. The sub themes are summarised in Table 27.

	SUPERORDINATE THEMES									
P	Blame	Causal links	Diagnosis	Food/weight	Information	Life style	Mood	NHS Issues	Self identity	Testing
F	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
J			✓	✓				✓	✓	✓
L	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Ma			✓	✓				✓	✓	
My	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 26 Shared themes in self-management across participants

SUPERORDINATE	SUB THEMES	
BLAME	External: others, media, health services Internal: self	
CAUSAL LINKS	Variable control Professional understanding (lack of) Personal understanding (lack of)	
DIAGNOSIS	Randomness of diagnosis Emotional response Management in life context Positive change	
FOOD/WEIGHT	FOOD Comfort eating Exclusion	WEIGHT Struggle Weight loss
	Cultural norms Lifestyle Identity	
INFORMATION	Complexity Contradictory Knowledge levels Tailored to individual	
LIFESTYLE OCCUPATION	Making positive changes Occupational adaptation Social occupations and norms Lifestyle priorities	
MOOD	Emotional response Mood and control	
NHS ISSUES	Appointment timing Competing priorities Interest in individual Support	
SELF IDENTITY	Beliefs, values and patient role Identification with diabetes	
TESTING	Frequency and appropriateness Impact of readings	

**Table 27 Shared themes in self-management with sub themes**

### **12.4.1 Study 3 Blame**

The issue of blame was discussed by three participants. The idea that type 2 diabetes is ‘self inflicted’ was a message that was prevalent in the social media, radio and newspapers at the time of the interviews (Browne et al, 2014). This included the view that people with diabetes had only themselves to blame, and were a burden and a drain on the health service (Browne et al, 2013). In some cases this view was also perpetuated by acquaintances. Frank commented on a

diabetes blog discussion where people with type 1 diabetes criticised those with type 2 and stated they did not want to be given the same label. The impact of this negative message was raised by participants to describe not only anger at being labelled as such but also to describe how unhelpful and demotivating this could be. Similarly being blamed by healthcare professionals for apparent lack of control of blood sugars was not only seen as frustrating and disempowering but also counter-productive. One of the participants queried whether she was herself to blame and another criticised herself for "*always failing*".

*I think people blame, yeah. You're a burden on the NHS, you're doing this and that's some of the messages that are coming out, certainly this week, some of the messages. (Frank)*

*Is it just because I'm too fat, haven't exercised enough', you know? And you kind of think oh. And then now when people present that idea to me, even though they're not as blunt as , 'you've done that', if there's even so much of a hint of a suggestion that people are saying that I've done this to myself, I get quite annoyed (laughs) and quite defensive! (Marilyn)*

Frank gave an example of where, following injury, he was specifically told that he was not being blamed for his diabetes. He did not, however, feel that this was widespread:

*The consultant team, anaesthetist, everybody else, were very careful to say 'we're doing this because you've got diabetes and of course that's not your fault'. (Frank)*

Issues of self blame also appear in the literature, particularly in terms of shame and embarrassment at not controlling blood sugars (Ingaddotir and Halldorsdottir, 2008).

### 12.4.2 Study 3 Causal Links

The frustration of not being able to make definite causal links between food intake, exercise or mood and blood sugar levels were significant for three participants.

Putting in effort to manage sometimes resulted in no apparent improvement and became demotivating. For one there was *"no rhyme or reason to it"*. Related to this was the difficulty of getting appropriate answers from professionals to make sense of the apparent randomness of causal links, and a questioning of the appropriateness of types of measurement (eg blood sugar levels) to signify 'control' over diabetes:

*I want to know why my body works against me. What's actually happening, the mechanism that's actually going on.* (Louise)

*Yeah, well there's a link when it goes wrong to getting annoyed and frustrated and then other days I might not realise without testing that something's high or low but I'm thinking 'why do I feel so miserable?' or whatever and then I'll test and think 'oh maybe it's this'. But I still don't know for sure.* (Frank)

*But now it's like I feel like I'm putting in that much effort that there are no more changes to make so if I don't see a positive reading now, it's just too much for me to handle. I just think, 'oh gosh there's no point'.* (Marilyn)

Instances of high or low blood sugar levels occurring without warning are apparent in the literature (Amorim et al, 2014) and understanding the mechanism is often seen as frustrating (Nagelkerk et al, 2006; Watts et al, 2010).

### 12.4.3 Study 3 Diagnosis

Four of the five participants were diagnosed 'by chance', having gone to the doctor for other tests. Emotional responses to that diagnosis included fear, grief, denial, and mourning. Metaphors to describe this included feeling like having been "*punched in the stomach*" or being "*heartbroken*". For others diagnosis metaphors included being stopped "*slightly in my tracks*"; being able to take it "*in my stride*"; being a "*tipping point*" or a "*nudge*" to make changes; and then getting on the "*right track*" or "*on the straight and narrow*". Other themes around diagnosis related to managing it in the context of life events and not wanting it to become a dominant part of life when other aspects of life were more important. Making changes after diagnosis were important to all participants and all made an effort to include healthier lifestyles. For many these were seen as positive changes but were not always easy to sustain:

*But as soon as they said 'well you do know you've got diabetes type 2' I said 'oh fair enough, right what do I do next?' And that's it. All I had to do is ask the question 'what do I do next?..... Now I have this confidence now, I feel better in myself and I don't have trouble with my knees now because I'm not carrying so much weight so it must be helping everywhere else. (Margaret)*

*It [diagnosis] was an opportunity to have some sort of discipline over my eating habits. (Louise)*

Making positive changes following diagnosis is not always the case. Watts et al (2010) found some participants who initially dismissed the diagnosis and paid no attention to managing their diabetes.

#### 12.4.4 Study 3 Food / Weight

Love of food and managing weight concerned all participants. For some food was part of lifestyle which included social events arranged around friends and food, and they described themselves as 'foodies'. Having to make different choices or have food choices made for them by others was problematic (Amorim et al, 2004). For others, food had a role as a comfort when times were difficult and having to make changes to diet were seen as having "*that crutch*" taken away. Louise described food as a "*monster*" which "*overwhelms you occasionally*". Generally having to make choices about food was seen as a kind of deprivation and there was concern that giving up certain foods would make life "*a bit boring*". Giving in to temptation was also an issue for some (Ingaddotir and Halldorsdottir, 2008).

Being described as overweight (according to BMI charts) was for some difficult to accept, especially as it appeared that losing weight was no longer an optional choice. In addition there was concern that certain diabetes medications could result in weight gain (Goebel-Fabbri, 2008). Others had no problem with describing themselves as overweight, noting that this was just the way they had been since childhood and that life events and growing older had increased weight gain. Diets had been tried, weight lost and put on again and motivation was a factor in being able to sustain any changes. "*Struggling with weight*" was seen as a "*curse*" by one participant and a "*worry*" by others.



### 12.4.5 Study 3 Information Issues

Three participants struggled with the complexity of diabetes information, and experience of diabetes education from healthcare staff was seen as disempowering, patronising and contradictory. Many felt that information was not up-to-date. Metaphors related to diabetes information included facts being *"like pieces from different jigsaws"*, and managing *"conflicting"* and *"woolly"* information being like negotiating *"a minefield"* with *"many grey areas"*. Information provision was seen as *"pitching to the lowest common denominator"*. Marilyn felt that information was being withheld as though *"there are cards being held back"* while Louise described the difficulty of finding answers as *"bumping into closed doors"*. Discussion also centred on what sort of information would be helpful, at what times and in what form. While acknowledging the complexity of diabetes, these three participants reported that information tailored towards the individual rarely happened and that what they were given was too simplistic:

*I don't know what's informing this guidance that we're being given, you know, because it doesn't make sense.* (Marilyn)

*'What are you going to do to help me, given that I know all this stuff. Are you going to tailor your information to me'. And when it doesn't happen and it's still the basics I then get frustrated and think 'thanks, that's another hour wasted'.* (Frank)

*I know that I would be much more successful if I was actually involved in my own management in a more clinical way with people who I believed knew what they were talking about.* (Louise)

Gomersall et al (2001) suggest that the complexity of information relating to diabetes and difficulties with communication with healthcare professionals are seen as a threat to a person's sense of self. They argue that the potential for

succeeding or failing in terms of diabetes control has the potential for this sense of self to feel under attack. Three of the participants discussed the problems of not getting the right information at the right level (their experiences were that they felt it was too simple and patronising), and the threat to sense of self came from not feeling empowered to make joint decisions or be autonomous in their dealings with healthcare professionals (Anderson and Funnell, 2010; Funnell and Anderson, 2004).

#### **12.4.6 Study 3 Impact on Lifestyle and Occupations**

As discussed in the section on food / weight (above), for many of the participants significant aspects of social occupations centred around friends and food. Culturally food is given as a present and this was seen as frustrating and difficult to manage from well meaning friends. For two participants spontaneity around food choices had gone, both in what to eat and in the practice of dropping round to see friends for a meal:

*I've avoided eating at my friend's, whereas before I used to go over quite often, chat after work and spend the evening there and eat with my friends. And I avoid it now because I don't, I know when the evening meal's being planned I'm not equated into the decision of what's being cooked and it would be awkward for me..... it's sad.*  
(Marilyn)

*It's so kind, it's so thoughtful but I would much rather people gave me permission to say 'no thank you' and I feel that that choice has been taken away from me by people doing something specially for me and misunderstanding diabetes.* (Louise)

Participants felt excluded from some events and also felt a pressure to conform to 'normal' eating from some people (Amorim et al, 2004). For Louise her sense

of self was challenged by all the deprivation she envisaged around diabetes. She described powerfully how, on first being diagnosed, she felt unable to buy anything from the shelves of a supermarket and suddenly felt as though she has been "excluded" from society. Although this had changed over the years she still felt that her diabetes had robbed her of her sense of spontaneity and that the need to refuse friends' hospitality not only kept her excluded from others but also feeling uncomfortable and not feeling normal (Ingadottir and Halldorsdottir, 2008):

*Separate again and feeling guilty as though you are somehow spoiling other people's pleasure. (Louise)*

This contrasts with other people's experiences of diabetes, who judged their lives as 'normal' despite the number of changes that needed to be made (Amorim et al, 2004).

Diabetes got in the way of managing a lifestyle that was important to individuals and some felt a pressure to ensure they lived their particular life, rather than one prescribed by the health service. For others the impact of other life events eg illness or family matters meant that the focus was not always on diabetes:

*Well I don't necessarily want a cure, I want to be able to see and to breathe and everything else, to get on with my life. If you can show me a way of doing that I'm interested. (Frank)*

*And people are so disappointed if you say, I just can't do it. (Louise)*

Other themes around lifestyle and occupation included making positive lifestyle changes following diagnosis:

*I don't enjoy my diabetes. I appreciate the changes I've made to my life because of it and like those changes and I'm glad I've made those changes. (Frank)*

However, participants also found that making changes to habits and routines could be difficult, in terms of medication or testing, or buying different recommended food items:

*They told me to test twice a day but the problem is they say to test like two hours after food and sometimes instead of having a meal I'll graze. (Marilyn)*

*But if you're a pensioner and your money's limited you're going to go for something that's near enough the same but a lot cheaper. (Margaret)*

Other adaptations were required to continue to engage in preferred occupations:

*If my pager goes off at One in the morning, I can't think 'I'm going to use this amount of energy therefore I'd better eat something right now'. But it does mean that I've made a change to what's in my pockets, what goes in my bag, stuff like that and I manage more as I'm going. So I am adapting. (Frank)*

#### **12.4.7 Study 3 Mood**

Diabetes affected participants in different ways. The two sub themes included an emotional response to diabetes, plus the link between diabetes control and mood. Only one participant reported that she had no anxiety about her diabetes due, she explained, to being well looked after. Other participants described feeling fear (Ingaddotir and Halldorsdottir, 2008), annoyance (Amorim et al, 2014), anxiety and frustration (Nagelkerk et al, 2006), confusion (Watts et al, 2010), guilt (Browne et al, 2013), and loneliness (Whisman, 2010):

*There are lots and lots of pressures which is why I mentioned the psychosocial side of it. I think your brain feels as though it's in a vice sometimes because of the worry of it and every time you slip slightly the guilt and it actually isn't at all helpful. (Louise)*

*I think there's always an edge to how you're feeling (pause). There's always something, you worry about what's going to happen next, you worry about long term implications for you, for other people and also just what's happening short term.*  
(Frank)

Low mood was an issue, especially when it appeared to be unpredictable in relation to diabetes symptoms and where participants did not feel that they had control over their diabetes (Skinner, 2004):

*And I know that if I do certain things I control the mood and other times when I'm not able to do those things my mood can swing quite a lot.* (Frank)

#### **12.4.8 Study 3 NHS Issues**

The themes under NHS Issues were to do with support and included appointment timing (Wellard et al, 2008); competing priorities (Watts et al, 2010; Zoffman and Kirkevold, 2005); interest (or lack of) in the individual (Skinner 2004).

For three of the participants the time delay between appointments was significant. In most cases this is six months which participants felt was too long to wait to see whether new medication was working, or to get reassurance that changes made to diet and exercise were appropriate:

*But personally, even though having this six month check up, which I've been told after doing all my tests and everybody's happy with what's going on, to me six months is a long time. Thinking about it, trying to do my best, am I doing it right?*  
(Margaret)

There were also positive experiences expressed, particularly from one participant who felt that the six monthly checks were a comfort and she felt well looked after:

*What I am impressed with is the follow-up which is constant, eye tests, blood tests, all sorts of things. I'm hugely impressed with the service and care and attention that you get, getting flu jab and all those sort of things. I take my hat off to the NHS.*  
(Josephine)

Being able to integrate or accept diabetes is advocated by health professionals as the main way to achieve control (Edwall et al, 2008; Handley et al, 2010). This was seen as problematic by participants because by accepting diabetes it was seen, paradoxically, as letting the diabetes control them (Watts et al, 2010). This was more of an issue for Frank and Louise who had had diabetes for a number of years. Louise commented that trying to achieve control was akin to *"fighting against your humanity"*:

*Because the more you try to control yourself, the more you think about it.....So that's another pressure. There are lots and lots of pressures.* (Louise)

Although the NHS was seen as a *"safety net"*, Frank likened professional advice to the programme on a washing machine:

*It's a bit like being in a washing machine, you're just tumbling. And now and again somebody opens the drawer and pours something in, clicks it and that calms it down or whatever.* (Frank)

Concern was expressed about the approach taken and a lack of individual attention:

*No-one's actually saying 'is this the right programme'..... 'is he on the right spin setting' .....Well you can't even tell it's a body can you, just spinning round, it's a lump, and every lump's different. And I don't think enough of the service is geared for difference.* (Frank)

Despite the range of potential approaches to diabetes management, this was seen to be constrained, although it was not clear whether this was an individual or service-led occurrence:

*And the feeling I get sometimes is that there are all these, it's like there are so many things in a toolkit but to me the toolkit that people have in a diabetes service seem to be limited. (Frank)*

In addition participants described relationships with professionals in terms of battle and power. One found she was “*constantly reprimanded for lack of control*”, and felt pressured: “*it's that feeling of being naughty, that you're constantly being scolded and it isn't helpful*”. This can leave people feeling “*victimised*”.

Issues raised included expectations of whether the NHS was there to support, to intervene or to prepare people for a lifetime of management:

*I don't know to what degree the health service had helped me be prepared. They've thrown me the life raft now and again, throw line whatever with some drugs on or whatever it might be but they haven't really helped me prepare for the journey, I don't think. (Frank)*

Compliance with healthcare advice is seen as the way to achieve control and make successful lifestyle changes (Gillies et al, 2007). Three of the participants commented that they made attempts to comply because they feared that if they did not, they risked losing the safety net of the NHS. This was despite the fact that they felt that intervention was not adapted towards themselves as individuals, which is the focus of the National Service Framework for Diabetes (DOH, 2001). Participants discussed the problems of a ‘one size fits all’ approach. Frank saw healthcare advice as being focussed on test results:

*It's 'let's have a look at your weight, let's have a look at your blood sugar, your blood pressure, you're high'. It's all 'let's look at the numbers'. (Frank)*

Whereas what he was after was someone interested in him and his life:

*Well I don't necessarily want a cure, I want to be able to see and to breathe and everything else, to get on with my life. If you can show me a way of doing that I'm interested. (Frank)*

#### **12.4.9 Study 3 Self Identity**

A diagnosis of diabetes was seen by Marilyn as a fundamental challenge to her beliefs about herself and the world. Having to take medication was literally "*a bitter pill to swallow*" as it compromised her beliefs about natural healing and her distrust of processed things. Issues around being a 'patient' or an 'expert patient' were discussed generally in interviews. Being seen as a patient by healthcare professionals was viewed as being problematic. As Frank summarised:

*I don't want to be an expert patient. I don't want to be a patient ..... I don't want to be good at being a patient ..... I'm not your patient, I'm my life. (Frank)*

Participants reported that healthcare professionals did not value people for who they were and stated they felt labelled as 'diabetics' with particular expectations and assumptions that did not often reflect their subjective experience. Participants preferred to describe themselves as a person with diabetes rather than as a diabetic, meaning that the individual rather than the condition was uppermost. Louise acknowledged that identity also impacted on how people managed their diabetes:



*And of course I suppose with diabetes you've got an overlay of all sorts of other personality traits, haven't you. (Louise)*

Challenges to long held beliefs and being identified as a patient were also a threat to self (Watts et al, 2010). For Frank, this was a particular difficulty and he resented the fact that he was seen as a patient and not for who he is. He explained this with the metaphor of a rucksack:

*Well I suppose 'I am a person with diabetes' is me saying I have this relationship with my illness, I have it, it's there, it tags along with me, just the same as a rucksack does. However I am not my rucksack. (Frank)*

Frank made every attempt to distance himself from being seen as a condition and had a strong sense that it was important for healthcare professionals to see him as the individual he is:

*And I really don't like sorts of people who say 'I'm a diabetic' because I'm not. I'm whatever I am, I have diabetes. (pause) And that might sound a bit nit-picky but that's what it is in my head. I don't want to be seen as my condition, I want to be seen as me. (Frank)*

Hasselkus (2011) argues that a focus on the bio-medical aspects of disease or illness means that humanness can be lost. People are identified as the illness and objectified and labelled as a clinical identity – 'a diabetic' for example – and thus identity and self are at risk. This appeared to reflect the experiences of some of these participants.

#### **12.4.10 Study 3 Testing**

Testing was an area where nothing appeared straightforward. Some participants deliberately did not test because they knew that high readings would make them

feel negative. Some tested routinely while others checked hardly at all. Others tested in "spates":

*If I know the readings are going to be higher I don't want to confirm it because I know that by confirming it my morale drops, if you know what I mean. And it's almost like I don't want to put myself in a down mood. (Marilyn)*

Test results/readings were seen as only being 'normal' for perhaps two hours per day so choosing times to test, and the difficulties of testing after meals if the pattern is to 'graze' instead became problematic. In addition one participant queried whether this was an appropriate measure:

*I think that most Type 2 diabetics are probably struggling with the same problem, and because their control is gauged by HBA1c blood glucose tests (which measures an average glucose level over 3 months), it's almost as though it's an inappropriate measure for their 'control'. (Louise)*

Some participants tested when they felt 'odd' to see if there was a specific reason. However 'good' test results were seen as motivating:

*My reward now is to see a low reading, that's the bonus, and I'm a sucker for it, I'm a sucker for pats on the back and I'm a sucker for a reward. (Marilyn)*

These views on blood sugar testing appeared to match those in the literature. Variable testing frequency was found by Thompson (2014) and Montez and Karner (2005); testing when unwell to find causes (Ingadottir and Halldorsdottir, 2008; Thompson 2014); impact on mood (Ingaddotir and Halldorsdottir, 2008; Lutfey, 2005); difficulties with problem solving and testing (Hill-Briggs, 2003).

### 12.4.11 Study 3 Summary of Themes

In making sense of these themes, it is clear that there are a number of overlaps and Figure 29 proposes how, for these participants, the themes relate to each other. In the centre of the figure is the diabetes diagnosis and the changes that are made as a result of this diagnosis. The inner circle depicts self identity, mood, and food/weight themes which are pertinent to the individual and impact on and are impacted by changes made as a result of diagnosis. The next circle shows how these individual aspects are influenced by and have an influence on the themes that are external to the individual: testing, information, and NHS interactions, along with making sense of causal links and blame. The outer circle represents the significance for the participants' lifestyles and occupations which, in turn influence all these aspects of diabetes management.

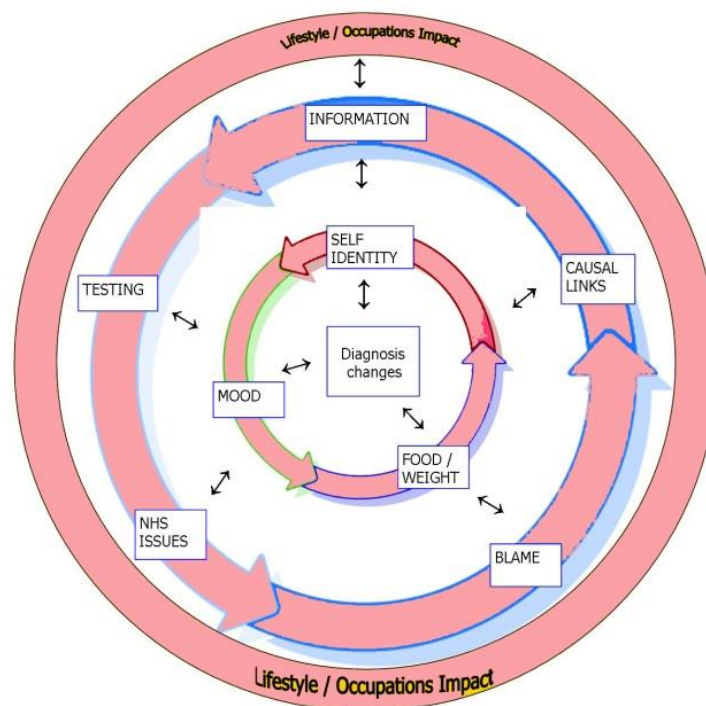


Figure 29 Relationship between self-management themes

Figure 29 can be further explained by considering these findings in relation to the literature on self-management in diabetes. In general the findings reveal that managing diabetes is a complex balancing act (Gomersall et al, 2001; Ingadottir and Halldorsdottir, 2001). With the exception of Josephine, who felt that her diabetes did not really affect her in any way, all of the participants faced barriers to management (Hall et al, 2002). These were related to managing obstacles (Andersson et al, 2008), (particularly reflected in Marilyn's metaphor), which consisted of negotiating treatment options, coping with low mood, dealing with blame, and struggling with both information and symptom control. Further discussion of the impact on lifestyle and occupation for all twenty-two participants is considered in Chapter 13.

### **12.5 Study 3 Diabetes Management Issues in Relation to Occupational Therapy**

The second part of this third study was to consider occupational therapy's role in diabetes self management in the light of the occupational therapy findings of study 2 and in the context of the issues raised by the participants in this study 3. Table 28 summarises the three main concerns that participants raised in relation to managing their diabetes.

Main theme	Sub themes
Impact of diagnosis	<ul style="list-style-type: none"> <li>challenge to values</li> <li>stigma</li> </ul>
Lack of support	<ul style="list-style-type: none"> <li>trust in diabetes healthcare staff (information and advice)</li> <li>having a say in treatment options</li> </ul>
Impact of or on daily routines	<ul style="list-style-type: none"> <li>eating, testing and medication</li> <li>choices in food buying and usual meal preparation</li> <li>eating out, meals and social activities with friends</li> <li>adapting to (and dislike of) exercise routines</li> <li>work routines and finding appropriate food choices</li> <li>family routines</li> <li>managing change</li> </ul>

**Table 28 Summary of Study 3 participants' concerns**

Participants were also asked about their positive experiences, and what they felt would improve matters in relation to their concerns. Table 29, which summarises those potential solutions, is compiled from answers across all the interviews, tying into the 'citizen outcomes' recommended in Commissioning for Outcomes (NHS Commissioning Assembly, 2014). These appear in the order in which they were proposed rather than in ranking.

Potential solutions to improve diabetes management
<ul style="list-style-type: none"> <li>Diabetes support group</li> <li>Diabetes buddy</li> <li>Being given the opportunity to consider / talk about own experience</li> <li>Clear information at the right level</li> <li>Understanding / being interested in the individual</li> <li>Understanding and recognition of impact of/on individual daily lives</li> <li>Mindfulness (mindful eating)</li> <li>Focus on motivation</li> <li>Skills for life (not just education)</li> <li>Holistic psychosocial support</li> </ul>

**Table 29 Study 3 participants' solutions to improve diabetes management**

Of the ten solutions listed in Table 29, six (S.1-S.6) are particularly pertinent to occupational therapy in terms of skills, values and beliefs (Creek, 2003):

- S.1. Understanding / being interested in the individual
- S.2. Understanding and recognition of impact of/on individual daily lives
- S.3. Focus on motivation
- S.4. Skills for life (not just education)
- S.5. Holistic psychosocial support
- S.6. Being given the opportunity to consider / talk about own experience

The following section considers the ways in which these six areas are applicable to the profession.

#### **12.5.1 Study 3 Occupational Therapy in Relation to Participants' Solutions**

In relation to the solutions that the participants proposed, it is clear, as outlined in Chapter 4, that occupational therapy has at its core understanding of the individual (S.1.) rather than the condition (CAOT, 2007). This includes encouraging the person to talk about their experiences (S.6.) and the personal meaning of their condition (Clouston 2003; Finlay, 2004; Peloquin, 1993; Polkinghorne, 1996). In relation to understanding and recognition of the impact of a condition or illness (in this case diabetes) on individual daily lives and the impact of daily lives on conditions (S.2. and S.4.), this also forms part of the skill set of occupational therapists (Fleming, 1994; Mattingly, 1991a).

By using a conceptual model such as the Model of Human Occupation (Kielhofner, 2008) occupational therapists can focus specifically on the volition, habituation and performance capacity of individuals. Thus a focus on motivation (S.3.) is incorporated in this view. By taking account of the physical and mental abilities within performance capacity, and the subjective experience that underlies occupational participation, occupational therapists can address both psychosocial holistic support and skills for life (S.5.) (Sumsion, 2010).

Further to the previous discussion on self care (see Chapter 5.3.3, p.73) occupational therapists could widen their view of self care to incorporate the occupation of diabetes self management for health and wellbeing and survival (Van Huet et al, 2010). This could include the skills of problem solving, enablement and environmental adaptation (Creek, 2003) to address possible practical issues of testing, injecting, medication, understanding food choices, making lifestyle changes in the context of the individual's own daily life (Pyatak, 2011a). More widely the occupational therapist could enable an individual with challenges to diabetes self management to engage in occupations that accord with their personal values and strengths and which enable healthier choices (Erlandsson, 2013; Pentland and McColl, 2008). Additionally the self identity issues raised by participants could be addressed through use of occupation (Christiansen, 1999). Further consideration of a possible framework for the role of occupational therapy in supporting diabetes self management will be discussed in Chapter 13.

It seems apt to complete this section with a reflection from Frank. He summed up concisely his perceptions of occupational therapy and what he thought occupational therapists needed to do:

*I was surprised when, having become an NHS governor, I went to do an inspection visit in a dementia unit where there were occupational therapists. And I thought 'why is there an occupational therapist? None of these people are ever going to work' because in my head that's what you did, you helped people go to work. And then I was shown that what they were helping the people in the unit to do was use a kitchen, to live a daily life, and I thought 'well I didn't know that occupational therapists did that, I thought they were about getting people back to work'. So there was a perception issue on my part. But if that's the skill of the occupational therapist to help people live a daily life, what are you doing to tell people how important a daily life is in the medical profession, and how they need to look at daily life. (Frank)*

## **12.6 Study 3 Summary**

This chapter has described the findings of study 3 in terms of the use of metaphor to understand the lived experience of diabetes, and discussed the findings in relation to the literature. The findings indicated that participants found it useful to discuss their experiences using metaphor and that it allowed them to consider more fully their feelings about diabetes. In addition the chapter examined the themes that participants raised about managing type 2 diabetes and proposed a model to describe the relationship between these themes. Potential solutions that participants proposed have been considered in relation to occupational therapy. A review of the core skills, values and beliefs of occupational therapy has found a congruent match with the participants' desired outcomes. Further discussion of a proposed framework for occupational therapy



practice in relation to diabetes will be considered in the next chapter. The following reflection relates thoughts about salutogenesis in relation to study 3.

***Reflection prior to Study 3:***

*I went to a session in Summer School on salutogenesis (Antonovsky, 1987) - this is a positive theory looking at what works and what went well (as opposed to pathogenesis - which is where we always look at the things that go wrong and therefore how we are going to improve them). This made me think more about my study - would it be possible to add in or highlight the things that are going right for the participants so that we can learn from them? I hadn't really realised before this that I was just assuming that people weren't managing (because of the increasing number of people getting diabetes and getting complications). Perhaps I need more emphasis in the following interviews of saying "well what did go well? What was helpful?". And perhaps what might help. Need to think further about how this might work. (July 2014)*



**Figure 30** Cutting up the quilt

*In my reading I had come across many examples of metaphors that are used in qualitative research, particularly that of the patchwork quilt. The concept of bricolage is also often referred to as quilt making. This got me thinking about how relevant the metaphor was and whether it was always apt and the only way I could decide was to have a go at making a quilt myself. I put together this piece with jelly roll strips but did not like the end product and so chopped it up to rearrange it. I learned that in quilting there was a process and an end product. Usually the pattern on the front is what most people refer to when they use the metaphor, but they don't talk about the sandwich of wadding in the middle and the backing material. Bricolage enables a number of different methodologies or ideas to get the different perspectives required to understand the area of research. These may not necessarily 'fit' together the way the pieces of a quilt do. Apt? I'm still not sure.*

## **13.0 Theoretical Discussion**

### **13.1 Chapter Outline**

The aim of this chapter is to draw together the three studies and consider the overall findings in relation to the research question. An initial review will be made of the limitations of the study. A return will be made to the research question to put the findings into context and to consider in what way the research question was answered. This will be followed by a consideration of the use of metaphor to understand the experience of diabetes. The lived experience of diabetes of the 22 participants will then be examined with the use of an occupational therapy theoretical model, the Model of Human Occupation (Kielhofner, 2008) to conceptualise the occupation of diabetes self management. A framework for occupational therapy practice in relation to the occupation of diabetes self management is proposed with consideration to the barriers and opportunities discussed in Chapter 11. The importance of the study, its contribution to new knowledge, implications for practice and suggestions for future research will follow in the conclusion in Chapter 14.

### **13.2 Limitations of the Study**

A discussion of the potential limitations of the study was begun in the Study Design Chapter under 9.9 Rigour, credibility and trustworthiness (p.174). This included issues around sample size (p.137), issues of power (p.143), the design of the study (p.175) and data analysis (p.176). Further consideration of the sample size and sampling method are discussed here.

This was designed as a qualitative study in order to understand the perspectives of those living with diabetes, the processes by which decisions were made about diabetes and how this fitted into daily lives. In addition it was designed to explore the possibilities for occupational therapy intervention in diabetes self management. This inevitably led to a small sample size of 22 participants which cannot be seen as representative of the whole population (Green and Thorogood 2009), although the review of the literature (Chapters 3, 4, 5 and 6) indicates many shared experiences with others managing their diabetes.

The purposive, convenience sample (DePoy and Gitlin, 2011; Smith et al, 2009) was predominantly White British middle class females, and thus could be seen as limited in scope and potentially biased (Ritchie et al, 2003). Attempts were made to mitigate this by selecting a range of ages, types of diabetes and length of time with the condition. The sampling, via word of mouth, conference posters and through social media, also meant that potential participants who did not participate in these activities may have missed out.

The lack of participants for the original third study (occupational therapists working in diabetes care) may have indicated that there was no role for occupational therapy. However another way of looking at this is that occupational therapists have not yet had the opportunity to practice in this area, and reflects the importance of researching this potential role (Packer, 2013).

While this study examines the lived experience of diabetes and proposes a framework for understanding diabetes from an occupational perspective (see sections 13.5 and 13.6 in this chapter), the nature of the potential occupational therapy is still theoretical. What limits this study is the lack of evidence for its use in practice. This forms part of the recommendations for future research, discussed in the Conclusion.

### **13.3 Research Question**

The research question was initially proposed at the end of the Literature Review (7.1, p.97) as follows:

#### ***Focus of research:***

The focus of this research was the role of occupational therapy in self management of diabetes, based on the life context rather than the medical aspects of this condition. The aim was to:

- explore the lived experience to understand how occupation impacts on and is impacted by diabetes
- explore the use of metaphor as a possible therapeutic medium to improve understanding of people's experience of diabetes
- explore the concepts and language of occupational therapy and how these limit or enhance the potential role of occupational therapy in diabetes self management

***In summary the research question was:***

What can be learned about the occupational experience of people with diabetes and how can occupational therapy enable health and wellbeing through occupation based self-management?

The separate findings of the three studies demonstrate the exploration of the aims of the study and they are further discussed as a whole in this chapter. As the findings are drawn together in this chapter the consideration of the potential answers to the research question unfold. Section 13.4 reviews the use of metaphor in all three studies as a means of understanding individual experiences of diabetes plus its potential as a therapeutic medium. Section 13.5 proposes a conceptualisation of the lived experience of diabetes as the occupation of diabetes self management (DSM). Section 13.6 extends this model to suggest a framework for the scope of occupational therapy in DSM which has, as its focus, the central philosophy of the professional belief in the impact of occupation on health and wellbeing (COT, 2014).

### **13.4 Use of Metaphor**

The use of metaphor was first introduced in the study (Chapter 9.6, p.152) as a means of analysis (Potter, 2001). Its acceptance by participants in study 1 as to the metaphor conceptualising their experiences (Youngson et al, 2015) led to further exploration in Studies 2 and 3 of its potential use as a way of enabling people to describe their own experience of diabetes. It was envisaged that this

might enable insights that would be different to assumptions about diabetes taken from a bio-medical perspective (Huttlinger et al, 1992).

The analysis of the pre-prepared metaphors of the 15 participants in Studies 2 and 3 revealed that two of the participants were unable to come up with a metaphor, although both used general metaphors in their discourse. Of these two participants one reported that she saw things in a very literal way and thus metaphor was not something she was comfortable with as a way of explaining her experience. The other participant reported being unaware of her use of metaphor. Kovecses (2015) suggests that people's experiences, situations and cognitive or experiential focus may govern how and, presumably, whether people use metaphors. Erjavec and Volcic (2010) in examining the use of metaphor to describe painful situations, commented that two of their nineteen participants did not use metaphor but there appears to be little else in the literature to indicate reasons for this. For the purposes of this study it is noted in so far as it may not be suitable as a therapeutic medium for all individuals.

For the other 13 participants, the use of metaphor to describe their experiences was welcomed by them and found to be useful. Having the opportunity to consider experiences before the interview was particularly valued, allowing participants to think about ideas and make connections (Gauntlett, 2007) and reflect on their diabetes in a way that was not generally asked of them.

Individually and collectively the metaphors used by participants gave insights into life with diabetes that may not have been evident otherwise. Among the 15 metaphors, four were journey metaphors: two kayak journeys, one taking the right path, one walking through fog. Two were sports metaphors of the steeplechase and the tug of war. Two metaphors had hidden, internal elements: the faceless enemy and the shadow, while another had a more overt symbolism of a second layer of skin. The remaining prepared metaphors reflected aspects of the participants' identity: losing weight, relationship to food, preparing for birth, and untidiness.

While it has been argued previously that self management of diabetes is complex (see 3.4.2 p.26) it can be argued that these metaphors give some insight into that complexity and to individual priorities (Funnell and Anderson, 2004). These individual perspectives are likely to reflect attitudes and emotions (Erjavec and Volcic, 2010) which could form the basis of an approach to problem solving challenges and integrating diabetes into daily life (Handley et al, 2010; Zoffmann and Kirkevold, 2005).

Although participants in Study 1 were not asked to pre-prepare metaphors to describe their experiences of diabetes, a return was made to the data to explore the metaphors used in general in the discourse of the interviews, and to compare this to that uncovered in Studies 2 and 3 (see Table 30). Amongst the three studies metaphors were used frequently in the discourse.



VEHICLE GROUPING (source domain)	METAPHORS COLLECTED INTO GROUPING	OVERLAP STUDY 2	OVERLAP STUDY 3
ART & CRAFT	fabric	cotton	wool
BUILDING/ CONSTRUCTION (inc materials)	barrier, brick wall, dimension, frame, props, ramped, window	barrier, frame, window	framework, window
CONNECTION	heart, bed fellows	relationship	relationship
CONTAINER	band, bottle, box, containment, (in) head, label, (in) mind, wrap in cotton wool	box, head, mind	box, head, mind
EDUCATION	school report, science lesson, told off	headmistress	n/a
FOOD / COOKING	haribo, salt, sweet (y)	sweet	menu
FORCES	brewing, bury, buries, chopped, danger, knocks, punches, rumbling, shed, shock, slapped, storm, waves	knock, shock, storm	knocks, punched, shock,
GAMES/SPORT	badge, boat, bounce, dive, diving, gold medal, jigsaw, juggle, left field, roundabout, run-up, running, swings, track, threw, yoyo (ing),	run, track, yoyo	jigsaw, juggle, running, raft, slide, swing, throw, track
MACHINES / TOOLS	ironed, line, parked, switch, tighten, tools	line, tools	tools
MILITARY	battle, battling, cudgel, stab, struggle	battle, struggle	battle, struggle
MOVEMENT/ DIRECTION	climb, dip, down, downhill, high, low, path, road, rocky path, route, slipped, slippery path, stray, up, U-turn, waltzing	down, downhill, high, low, path, route, slip, up	down, high, low, path, road, route, up
NATURE incs landscape, light/ dark, plants, animal	carrot, border (line), plateau, stick, tree	borderline, plateau	borderline
RELIGION	fiend, gods, spectre	devil	soul
RESOURCES	burden, clutter, drain, list, penny, stall	cost	gold
WARNING	Achilles heel	bells	n/a

**Table 30 Study 1 general metaphors compared to those in Studies 2 and 3**

Diagnosis of diabetes was one area that was examined in terms of general metaphor. Participants in Study 2 and 3 primarily used metaphors of movement/direction (see p.223 and p.271) to denote being stopped in one's tracks, or the start of a journey and the need to get on the right path. Other metaphors were concerned with forces such as the shock of diagnosis. Study 1 participants used similar forces metaphors to explain that symptoms had been

"rumbling" or "brewing" for a long time prior to diagnosis, but also that they felt "labelled" and part of a "box ticking" exercise.

In terms of DSM, movement/direction and military metaphors were prevalent in Studies 2 and 3 (see p.225 and p.281). For Study 1 participants there were similar metaphors of "slippery" or "rocky" paths; blood sugars "straying up or down", "running high" or "running low".

Returning to the Study 1 data to look for metaphors also revealed some interesting examples that gave insight into the meaning of individual experiences. Rachel described the ways in which she attempted to prevent development into type 2 diabetes in the following metaphor:

*You know when you go cave diving you hold onto the bit of string. I feel like I'm just about holding onto the string. And doing all this is part of the string.* (Rachel)

She later reported the refusal of the GP's surgery to supply her with a blood testing kit as:

*I wasn't seen as a sort of gold medal patient for asking for a meter, rather as a drain on resources.* (Rachel)

Those three metaphors: making and holding onto the string as a lifeline; feeling negatively like a drain on resources; wanting a gold medal for trying to take positive, preventative action, readily communicate the difficulty of self management and the potential for people to be put off making positive choices.

In summary, metaphors advance the understanding of individual experiences of health conditions (Penson et al, 2004; Mallinson et al, 1996; Radley, 1995; Steslow, 2010). They have the potential to allow healthcare professionals to understand how individuals make sense of the world (Cameron, 2003; Cameron and Maslen, 2010; Lakoff and Johnson, 1980). The findings reveal the necessity to discuss metaphors with individuals so as not make assumptions about the experience being described. They also indicate the need to listen out for implicit metaphor use and the potential to explore these images for enhanced understanding. This indicates that theoretically the findings support the explicit use of metaphor as a therapeutic medium in understanding the lived experience of diabetes. However this would need to be put into practice to see if it can be effective in a non-research setting.

### **13.5 Conceptualising the Lived Experience as the Occupation of Diabetes Self Management**

As discussed in the Study Design chapter the findings from studies 1, 2 and 3 were presented following phenomenological and thematic analysis (Braun and Clarke, 2006; Finlay, 2011; Smith et al, 2009). As previously discussed in Chapter 9.9, in terms of rigour an attempt was made to consciously bracket out my professional understanding as an occupational therapist within the analysis, so as to avoid fitting the data to the theory (Dowling, 2006; Finlay, 2002a). Although it has been argued elsewhere (Chapter 8.7, p.126) about accepting that one's subjective experiences will knowingly or unknowingly influence the study (Bishop

and Shepherd, 2011; Bradbury-Jones, 2007; Cutcliffe, 2003; Finlay, 2002b), this was a deliberate choice to attempt to prevent missing the nuances of the data by potentially narrowing the focus into a preconceived occupational therapy framework (Nayar and Stanley, 2015) at that stage. Instead this was about opening up the data to other interpretations.

Drawing all the findings together of the 22 participants with some confidence that this was achieved, those findings are now considered in the context of an occupational therapy theoretical framework, that of the Model of Human Occupation (MOHO) (Kielhofner, 2008) in order to explore the understanding of diabetes self management from an occupational therapy perspective. MOHO was first introduced in the occupational therapy section of the literature review (Chapter 4.3.4 p.47) and is used here as one of the most commonly used theoretical models in practice (Lee et al, 2012). As described in the literature review, MOHO concepts address motivation for occupation, routine patterning of occupational behaviour, nature of skilled performance, and the influence of environment on occupation (Forsyth and Kielhofner, 2003).

Studies 1, 2 and 3 all revealed aspects of living with diabetes where participants described the realities of fitting the condition into their daily lives. Study 1, described in terms of the metaphor of charting a course of health and wellbeing through the choppy sea of life, revealed how aspects of self identity, individual action, the environment and relationships with healthcare providers all impacted on ability to manage diabetes. Study 2 showed similar aspects of the journey of

diabetes, the struggle for balance and control, plus the internal and external influences on participants' ability to make choices in self management. Study 3 revealed other journey metaphors, practical aspects of diabetes management, changes made as a result of diagnosis, the impact of diabetes on self identity and mood plus the issues of dealing with external pressures such as blame. The MOHO (Kielhofner, 2008) enables representation of all these different aspects in an occupational therapy theoretical framework.

The following diagrams summarise the findings from the 22 participants into the occupation of diabetes self management (DSM). Occupation is defined as *"an activity or group of activities that engages a person in everyday life, has personal meaning and provides structure to time"* (COT, 2004, p.2). Self management, as discussed in chapter 5, was defined by Barlow et al (2002, p.178) as *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"*.

This is reflected in the occupation of DSM which here is divided into seven main "occupational forms" (Kielhofner, 2008, p.105) as described by the participants. Aspects of management from type 1, type 2, gestational and pre-diabetes are described. Not every aspect is experienced by every participant (eg some participants with type 2 diabetes may be taking oral medication rather than calibrating insulin levels and injecting) but collectively they summarise the experience. For the most part participants described this occupation as

something that they attempted to manage individually, rather than sharing with family and friends. Figure 31 illustrates these seven occupational forms of DSM which are summarised as follows: managing appointments; managing diet; exercise; information and education; medication; managing other illness; and blood sugar testing. References are made to the literature which reveals that the occupational forms of diabetes self management are prevalent amongst people with diabetes although, as Fritz (2014) and Thompson (2014) argue, few researchers have seen diabetes from an occupational perspective.



**Figure 31 The occupation of diabetes self-management**

Starting from top right of Figure 31 and in the direction of the arrows, the following describes these occupational forms. Managing appointments includes preparation in terms of testing and recording blood sugar levels (Ingadottir and

Halldorsdottir, 2008; Rasmussen et al, 2007); information exchange (Watts et al, 2010); managing the therapeutic relationship (Funnell, 2004; Watts et al, 2010), especially where participants encounter different professionals on each appointment (Thorne and Paterson, 2001); engaging (or otherwise) with the scope of intervention (Holmstrom and Rosenqvist, 2005) and dealing with the frequency of appointments eg too often or not soon enough (Wellard et al, 2008).

Managing diet includes the need to make specific food choices (Brackenridge and Swenson, 2004), as well as over-riding the instinct to eat when stressed (Ingadottir and Halldorsdottir, 2008); abiding with daily recommendations for eg. fruit and vegetables (Gilis-Januszevska et al, 2011); timing of meals in relation to medication (Montez and Karner, 2005); carbohydrate counting (particularly for insulin users) (Thompson, 2014); weight control (Haslam, 2010); the use of a food diary and/or mobile technologies to maintain records or check food portions (Mulvaney, 2009). Exercise encompasses over-coming exercise reluctance (for some) to incorporate this into the day (Lutfey, 2005; Nagelkerk et al, 2006); and planning medication and sugar supplies to cover possibilities of hypoglycaemia (Montez and Karner, 2005).

Information assimilation and education incorporates attending diabetes courses (Moser et al, 2008); dealing with the complexity (Lutfey, 2005; Skinner, 2004) and timing (eg too soon, too late) (Nagelkerk et al, 2006) of diabetes information and tailoring it to one's own situation (Edwall et al, 2008); making changes to routines

as a result of training to allow for more flexibility in diet, particularly for insulin users who can adjust dose for normal eating (Snow et al, 2013).

Medication management formed a major part of self management for the participants. This involves managing the timing of medication or planning to ensure medication is available in relation to other daily activities (Montez and Karner, 2005; Rasmussen et al, 2007); dealing with changes to medication and possible risk factors (Hill-Briggs, 2003); incorporating new equipment (especially for insulin users of innovations in pens and pumps) (Montez and Karner, 2005; Phillips, 2007); calibrating insulin amounts in relation to diet and exercise (Gillibrand and Flynn, 2001) and making choices about where and when to inject (Thorne and Paterson, 2001).

Managing other illnesses involves distinguishing diabetes symptoms from other symptoms, such as flu, and making adjustments to medication or behaviour accordingly (Thorne and Paterson, 2001). This also includes being aware of and incorporating other conditions such as arthritis or epilepsy (Mavaddat et al, 2014). In addition participants felt the need to check out symptoms to check whether they were starting to develop complications (Phillips, 2007).

Finally the occupational form of blood sugar checking involves managing equipment (meters, lancets, strips) and deciding on the timing and frequency of testing (Hill-Briggs, 2003; Montez and Karner, 2005; Thompson, 2014); recording results (Ingadottir and Halldorsdottir, 2008; Thompson, 2014); the legal necessity



for testing when driving (Gill et al, 2002); and dealing with the emotional impact of the results eg high blood sugar level readings impacting on mood and/or being demotivating (Lutfey, 2005; Pyatak et al, 2013; Rasmussen et al, 2007).

In relation to Figure 31 the arrows indicate that these seven areas all inter-relate. The thinking bubble in the middle indicates the self and that all participants have decisions to make about how, what, why and when they will organise self management (Gillibrand and Flynn, 2001; Paterson et al, 1999; Watts et al, 2010). Although the occupation forms described above were common to the 22 participants, it is important to note that each person's experience of the occupation of DSM was different. Within the MOHO (Kielhofner 2008) this is explained by the occupational identity of the person; by their choices, beliefs, values, and interests (volition); by their habits, roles and performance capacities (habituation); and by the opportunities or demands of the environment (Parkinson et al, 2004). The occupational forms of the occupation of DSM also change with time, experience and other life events of the people concerned (Pyatak et al, 2015).

Figure 32 gives more detail about the interaction of the different components of self and the environment on DSM. In order to explain this further, Figure 33 takes one aspect of DSM (blood sugar testing) and demonstrates how these components provide opportunities or constraints for managing this task.

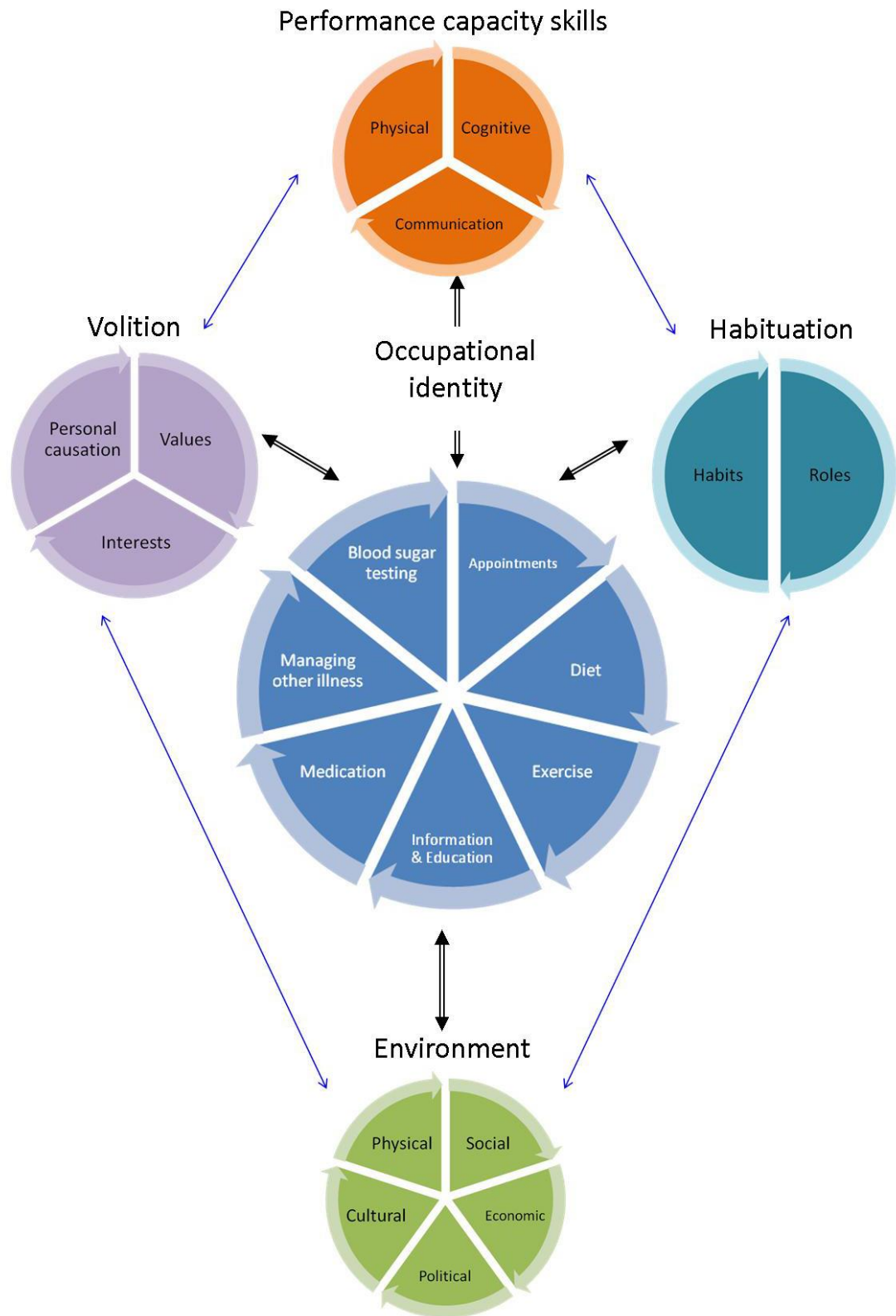


Figure 32 Interaction of occupation of diabetes self management with aspects of the person and the environment based on the Model of Human Occupation (Kielhofner, 2008)

Blood sugar testing is a task that all participants reflected upon. Figure 33 illustrates the impact of volition, habituation and environment, using the words of participants from all three studies.

It can be seen that blood sugar testing is not merely a physical task. The formation of new habits is required, it is impacted by job roles (such as the need to test before driving), requires learning, is value laden and is influenced by experience and beliefs (Thompson, 2014).

DSM needs to be accomplished in the context of the person's lifestyle, it being only one aspect of managing daily lives (Fritz, 2014; Gillibrand and Flynn, 2001). One other particular aspect of the findings was the recognition of the impact of occupations on the occupation of DSM and the impact of diabetes on other occupations (Thompson, 2014). This is illustrated in Figure 34.

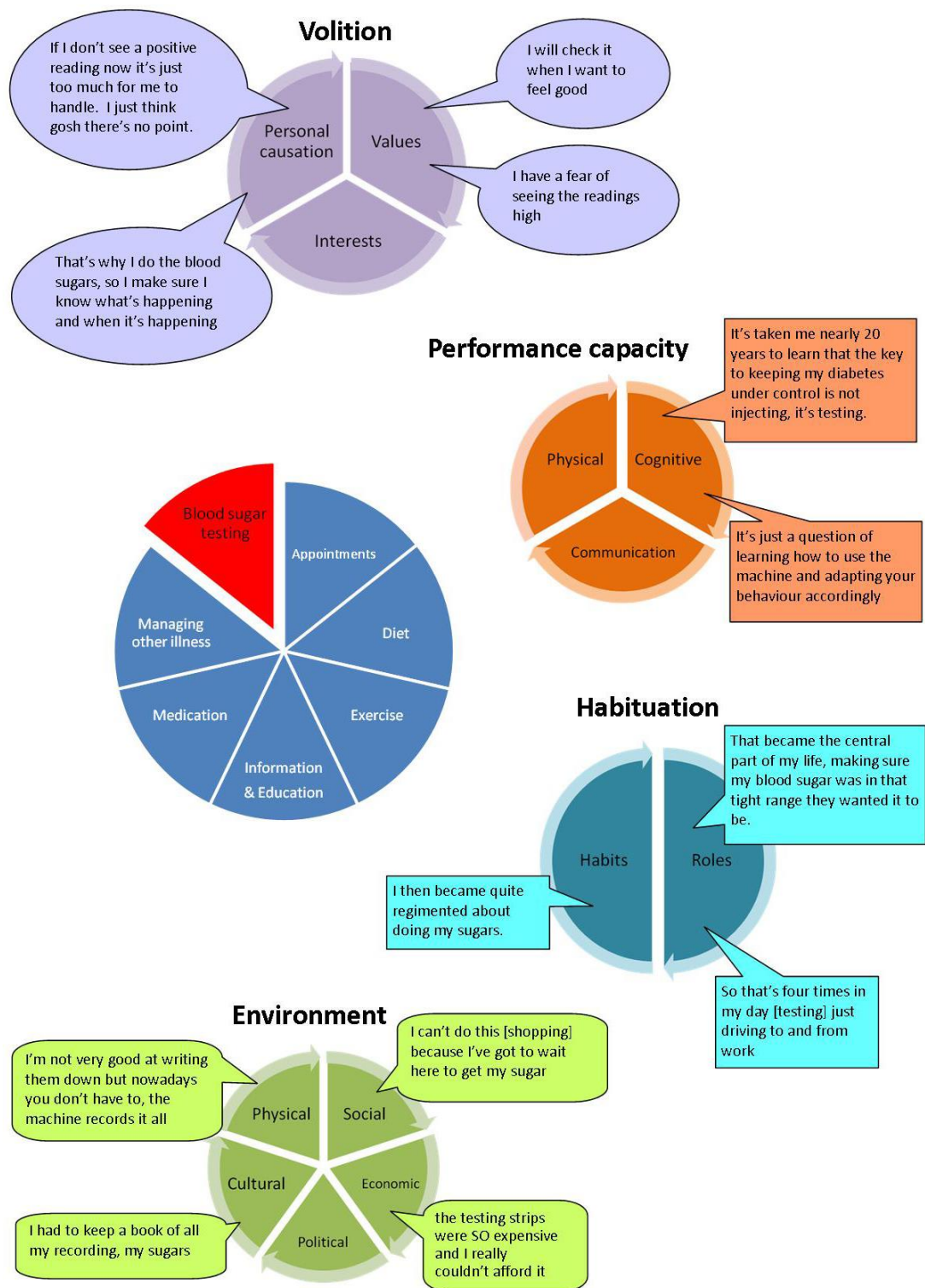
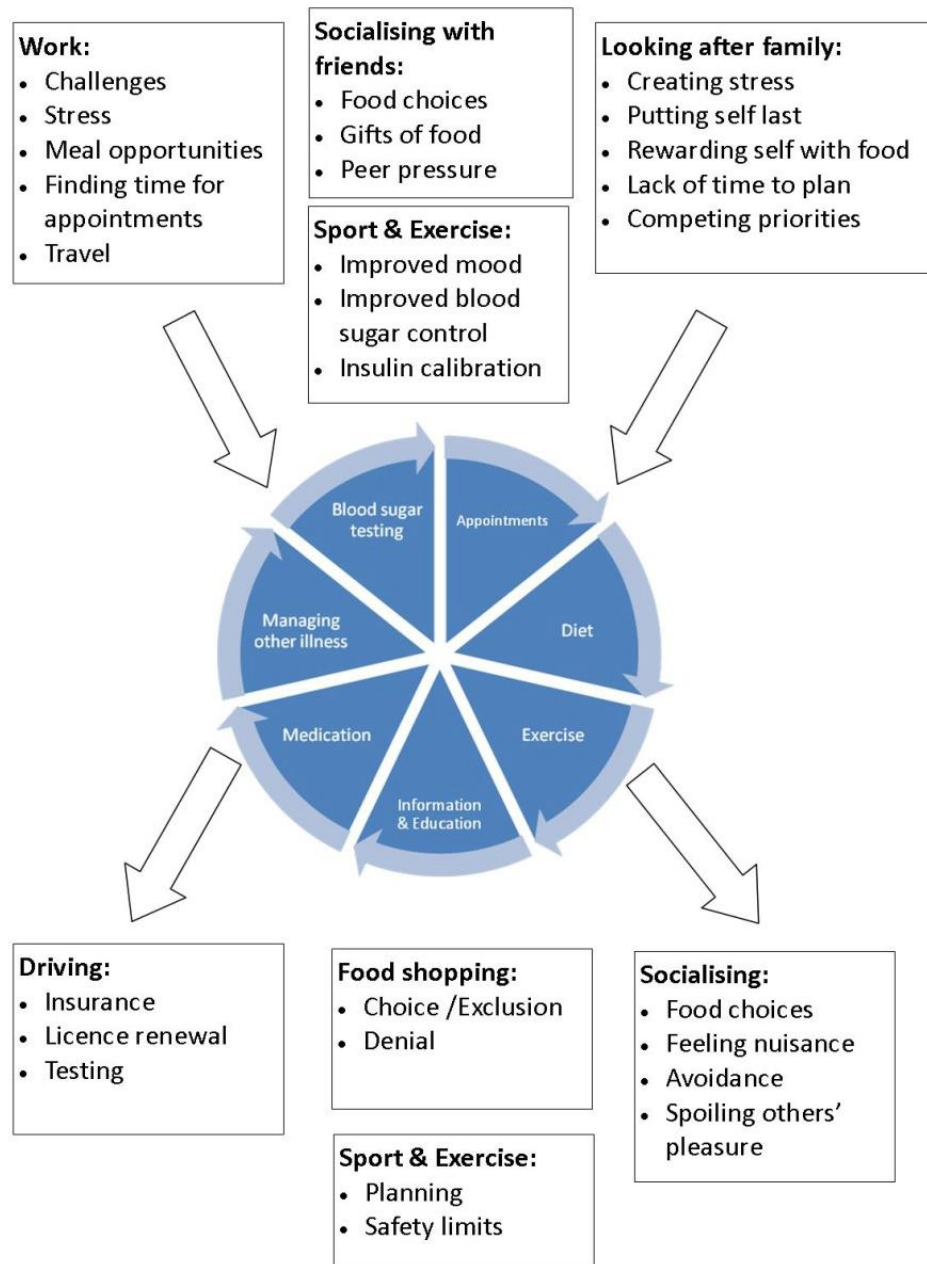


Figure 33 Blood sugar testing

### Impact of occupation on diabetes



### Impact of diabetes on occupation

Figure 34 Impact of occupation on diabetes and diabetes on other occupations

Participants talked about four main occupations impacting on their management of diabetes: work, socialising with friends, looking after family, and sports and exercise. The stress and challenges of work and family occupations had implications for occupational balance (Christiansen and Matuska, 2006) and led

individuals to reward themselves with food, which then impacted on blood glucose levels and weight control (Svenningsson et al, 2011). Additionally participants prioritised work and family life ahead of their own self management. Socialising with friends led to challenges and pressures about food choices, again impacting on diet, testing and medication (Wellard et al, 2008). Sport and exercise were occupations that participants described as having a beneficial impact on diabetes self management in terms of motivation, improved mood and better blood sugar control (Qiu et al, 2012).

Management of diabetes also had an impact on the pursuit of other occupations. The four main occupations discussed were driving, food shopping, socialising, and sport and exercise. Participants talked about the need to declare their diabetes for car insurance purposes, some difficulty over driving licence renewal and the legal requirement to test blood glucose levels (Gill et al, 2002). Managing diet, for some, resulted in reduced food choices and feelings of exclusion while shopping for food and having to make efforts not to give in to temptation (Wellard et al, 2008). In addition this impacted on socialising with friends in terms of trying to make healthy food choices while not inconveniencing dinner party hosts, negotiating the refusal of food gifts, and dealing with the emotional impact of feeling a nuisance or spoiling others' pleasure (Amorim et al, 2004). While sport and exercise had been seen as having a beneficial impact on diabetes management, it also required participants being aware of their safety limits and planning beforehand to ensure adequate supplies of medication or emergency glucose (Montez and Karner, 2005).

With reference to the study aims, to explore the lived experience to understand how occupation impacts on and is impacted by diabetes, this approach to the findings clearly illustrates these links. Looking at diabetes from an occupational perspective provides insight into the occupational forms of DSM and its relationship with other occupations. This differs from the traditional medical view of self management tasks by taking into consideration the individual in the context of their own daily life. Using the Model of Human Occupation (MOHO) (Kielhofner, 2008) further explains how the occupational identity of the person; their choices, beliefs, values, and interests; their habits, roles and performance capacities; and the opportunities or demands of the environment impact on that self management. This has not previously been reported in the literature and is a new interpretation of the experience of DSM. This increases the knowledge base with specific reference to DSM and occupation. The next section discusses how this approach to DSM could strengthen an occupation based occupational therapy intervention which is different to yet complements current medical practice in diabetes self management.

### **13.6 Occupational Therapy Role**

Chapter 11 (Study 2 Findings and Discussion) considered the issues around the language of the profession, the scope of practice and barriers to widening occupational therapy's role in health promotion in general. Despite some ambivalence amongst the participants about the role of occupational therapy in

DSM, examples were given of areas of practice that could be developed. Based on those findings and the discussion, plus the conceptualisation of DSM as an occupation above (Section 13.5), a framework for the scope of the occupational therapy role is here proposed (Figure 35).

There is a precedent in the literature when describing the role of occupational therapy to include intervention. Hammond (2004) when considering the role of occupational therapy in rheumatology, describes what it is that the occupational therapist does, lists interventions and summarises a pathway. Others use role and intervention synonymously (Penfold, 1996; Schatz, 2013; Udell and Chandler, 2000; Wilberforce et al, 2016) describing guidelines, frameworks and responsibilities. Perrin (2005, p.93) suggests, in relation to socialisation into the occupational therapy role, that occupational therapy's failing has been in explaining "*the essential nature of occupation to health and well-being*". It is argued that the role of occupational therapy in diabetes self-management can therefore be best explained here in terms of a framework for intervention that makes this role explicit while also demonstrating the links between occupation and health and wellbeing.

The College of Occupational Therapists' (2014) vision for the profession maintains that health and wellbeing can be facilitated by occupational fulfilment and that this central philosophy must form the basis of all occupational therapy intervention. Service delivery, while taking account of the political and social context of the work environment, should focus on both occupation and



occupational performance (COT, 2014). Taking the participants' views and the need to "*steadfastly embrace the power of occupation to transform lives as the central tenet of the profession*" (COT, 2014, p.2), the following framework suggests how occupational therapy could be applied to diabetes self management.

The proposed new framework for the occupational therapy role in DSM (see Figure 35) is adapted from the College of Occupational Therapists' explanation of the relationship between professionalism, knowledge and skills (COT, 2014, p.5). As can be seen from Figure 35, applying the core beliefs and values of the occupational therapy profession forms the starting point for this proposed new role. The person is viewed primarily as an occupational being facing an occupational challenge which requires transformation through occupation (Duncan and Watson, 2004). In this way the initial lens with which the individual is viewed is not focussed on the condition but on the wider context of the use of meaningful occupation for health and well-being (Townsend and Polatajko, 2007; Wilcock, 2006). From this I have proposed that the specific occupational needs of the person can be identified and the specific occupational challenges of diabetes self management (DSM) addressed.

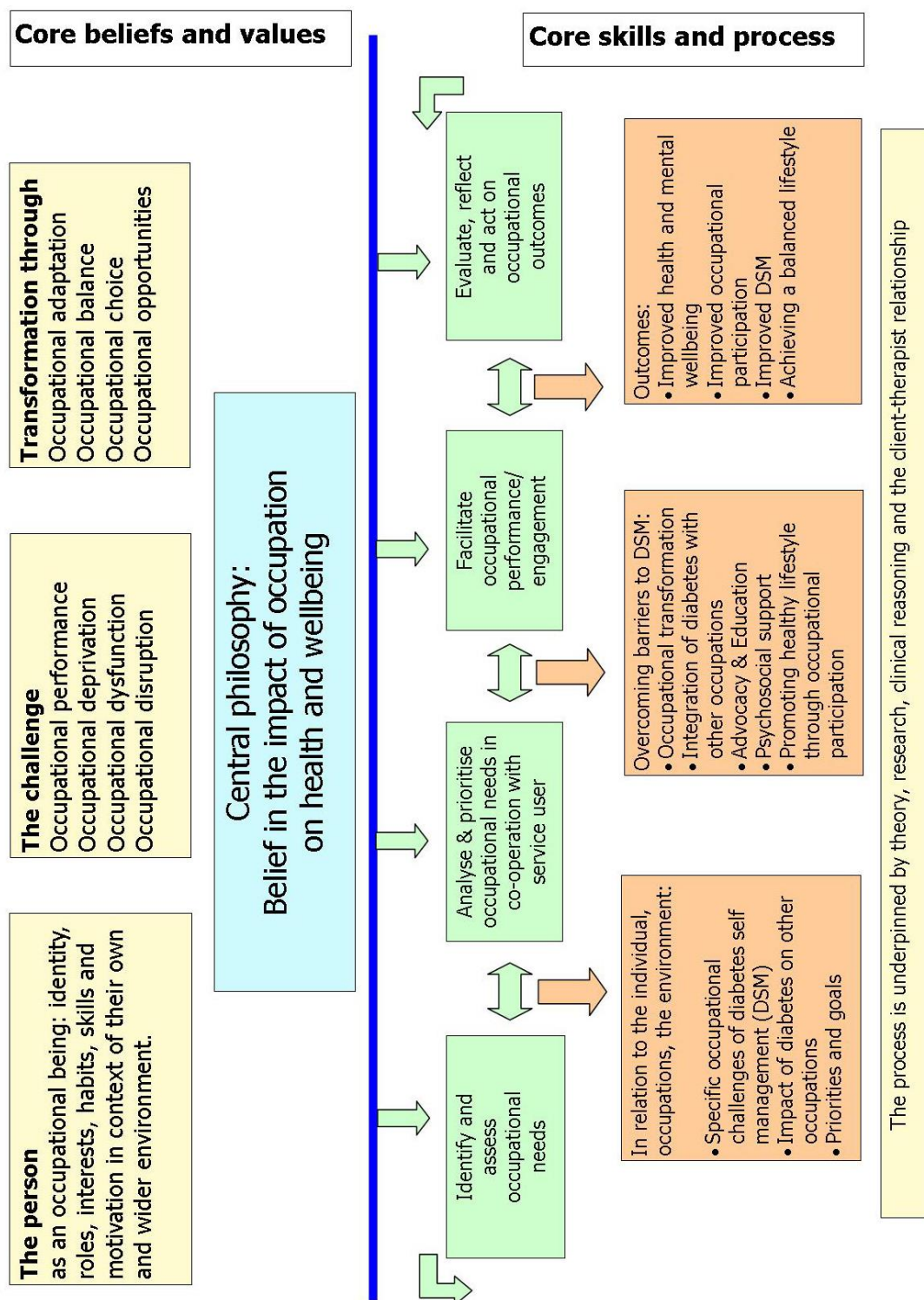


Figure 35 Proposed Framework for the occupational therapy role in diabetes self-management

(This framework is adapted from the COT (2014) Learning and Development Standards for Pre-Registration Education, reproduced with permission from the College of Occupational Therapists under the COT open permissions licence v1, 2013, <http://www.cot.co.uk/authors-resources/authors-resources>).

As detailed in Figures 31, 32, 33 and 34, challenges could arise in one or several of the occupational forms of DSM, and be related to occupational identity, volition, habituation or the context (environment) in which these take place. Additionally challenges may be related to the impact of other occupations on DSM and the impact of DSM on occupation. The occupational therapy role in terms of intervention then takes the form of prioritising and addressing the specific issue to promote improved DSM, health and wellbeing, a balanced lifestyle and occupational participation.

This framework could enable occupational therapists to focus on the potential of occupation for living well with diabetes instead of focussing on the need for occupational therapy once complications have reduced occupational participation (Piven Haltiwanger, 2012). It supports the opportunity to integrate DSM into daily lives (Fritz and Lysack, 2014; Pyatak, 2011b; Zoffmann and Kirkevold, 2005) by understanding and adapting routines (Fritz, 2014; Thompson, 2014). Above all it allows a perspective complementary to medical management, in enabling people to maintain or develop meaningful participation in all aspects of life and not just those directed at the health condition (O'Toole et al, 2013; Packer, 2013).

Use of such a framework may help to reduce some of the concerns expressed by occupational therapists in Study 2 around scope of practice, the language of the profession and barriers to applying occupational therapy to DSM. It achieves this by showing the explicit relationship between professionalism, knowledge and

skills (COT, 2014). It could also be used to address the challenge put to the profession by Frank during his interview as to how occupational therapists will explain about daily lives (see Chapter 12.6, p.288). The framework gives potential for occupational therapy to offer solutions to the main issues raised by participants in study 3 and meet the solutions (specifically S.1–S.6) proposed by participants for improving their diabetes self-management. It might also lead to the situation envisaged by Nancy:

*Wouldn't it be great if they [in GP surgery] said "why are you having trouble with your diabetes management, why are your sugars all over the place, maybe you should talk to the OT about some of your lifestyle things and see if they can't help you with figuring out how to integrate this better into your daily lifestyle, to keep this under better management". (Nancy)*

### **13.7 Summary**

This chapter has reviewed the limitations of the study and drawn the three studies together to consider the findings overall in relation to the research question. The three aims of the study: exploring the lived experience of diabetes, exploring the use of metaphor, and exploring the concepts and language of occupational therapy in relation to DSM, have been met. In terms of the research question, a model has been proposed to explain the occupational experience of people with diabetes, and a theoretical framework suggested to show occupational therapy's role in enabling health and well-being through occupation based self-management. The importance of this study and suggestions for future research are considered in the next chapter. The following reflection contemplates thoughts around this final piece of the study.

### *Reflections on the research process:*

*I went back to the writings of Robert Fritz - notably 'supercharging the creative process' about how we want to find quick answers and the intolerance it is possible to feel when you have no idea how to get to the next stage. He talks about this intolerance actually being one of the best moments where you can drive the creative process forward. I found a moment of resonance. I have been getting stuck in this final part of the study in to how to pull it all together. While convinced of the importance of seeing diabetes self management as an occupation and being able to see how this shows a specific difference to medicalising it, I couldn't quite visualise how the OT approach could be as well documented. I started playing around with diagrams but couldn't get it right. I realised that I wanted that quick answer just to get it finished. I decided to leave it for a while and check my emails instead. One was from BAOT talking about the new learning and development standards and their relation to CPD. I read the document and came across a model that looked like it could form the basis for the framework I wanted to portray. Hours went by as I played around with the possibilities and then when it looked like it could work I emailed COT for permission to adapt their model. Permission granted I then carried on. (August 2015).*



**Figure 36** Stitching up the thesis

*This first work was created two months after starting the study. I had been reading many books - on research and on occupational therapy - and my usual method is to read through a book, marking interesting passages with a post-it note. I then go back through the book, making notes on the places marked, taking out the post-it notes as I go along. At the end of that process I had a whole stack of post-it notes, and wondered what to do with them all. They reminded me of quilt pieces so I organised them into a quilt pattern and then stitched them all together. I incorporated the title with individually stitched letters and made the surrounding paper frame from random pieces of paper. I left the 'quilt' unfinished in the middle to represent all the gaps in my knowledge and filled that with images of question marks to represent my uncertainty of where it was going next. Most of the sewing lines are deliberately not straight as the whole experience of research appears not to happen in a straight line. There are many interconnected layers. Sometimes one idea strikes off another. The interest and colour symbolise the richness of this whole experience and the paper frame symbolises the layers of meaning and context around the study. Reflecting on this piece now that I am at the other end of the research experience, it still seems apt. There are still gaps, although I think these have been filled to a large extent, the lines are still curved and the experience still rich.*

## **14. Conclusion, Implications for Practice and Future Research**

### **14.1 Chapter Outline**

This concluding chapter discusses what is new about the study and why it is important. It addresses the contribution to new knowledge and implications for practice. Finally suggestions for future research are considered.

### **14.2 Contribution to Knowledge**

This thesis began by examining approaches to diabetes and diabetes self management, the values, skills and beliefs of occupational therapy, the context of public health in the UK, and the language of healthcare through metaphor. The interviews of the 22 participants were first analysed through a process of intuitive inquiry (Anderson, 2011) and the findings were presented within each study and then examined as a whole. The contribution to new knowledge is summarised below.

1. The findings add to the occupational therapy theoretical base with
  - a model of the occupation of diabetes self management
  - understanding of the impact of occupation on diabetes and impact on diabetes on occupation
  - a framework for occupational therapy intervention in diabetes self management to complement the medical approach

2. The findings add to general knowledge about diabetes through

- the lived experience of diabetes
- the use of metaphor to explain that experience

### **14.3 Implications for Practice and Suggestions for Future Research**

The research literature suggests that occupational therapists may not be adept at seizing opportunities to promote the skills of the profession in terms of health promotion and the prevention of ill health (Moll et al, 2013; Molineux and Baptiste, 2011). This is despite the fact that it has been recognised that occupational therapy has the beliefs and skills to incorporate health promotion (COT, 2008). There is evidence to suggest that the scope of practice of occupational therapy may have been narrowed due to practice contexts (Wilding, 2011), views of others of the profession (Ashby et al, 2015), professional language (Cooper, 2012) and beliefs held by practising therapists (Aguilar et al, 2013). There is, however, evidence that things are beginning to change in the UK in recent publication of the COT Code of Ethics and Professional Conduct (2015) and the Learning and Development Standards for Pre-Registration Education (2014) where the belief in the impact of occupation on health and wellbeing has a more central place.



This study, embedded in the experiences of those with diabetes, suggests that there is a role for occupational therapy in diabetes self-management, and that occupational therapy has a distinct role through seeing this self-management as an occupation rather than a medical approach. In addition the framework proposed goes some way (theoretically at least) to overcoming some of the barriers discussed, to suggest how the profession could complement the medical approach by explicitly showing the relationship between professionalism, knowledge and skills (COT, 2014) in an approach to enabling improved diabetes self-management for those that require it.

Further research is required to develop this framework and to ascertain how this will work in practice. An evaluation of outcomes is required, particularly in terms of improved health and mental wellbeing, improved occupational participation, balanced lifestyle and overall improvements to diabetes self-management. In addition economic evaluation of the approach is required (Rastrick, 2015) to enable occupational therapy to prove that it can help to deliver a sustainable health service focussed on prevention and self care (Kings Fund, 2015).

## **14.4 Conclusion**

The rising number of cases of diabetes is a concern for public health policy (National Audit Office, 2012) and the personal impact on the individual with diabetes is considerable. Approaches to diabetes self management that can help people to manage this condition and prevent further complications in terms of

the context of their own lives appear to be the way forward (Mulvaney, 2006; Nagelkerk et al, 2006). This study started out with the intention of devising an occupational therapy programme that would enable people to manage their diabetes. I gradually began to understand that my thinking was unwittingly influenced by the bio-medical culture (Molineux and Baptiste, 2011; Rogers, 1982) and that this proposed programme would likely have been not dissimilar to other approaches. What has developed, in response to listening to the experience, the language and metaphor, and the needs of the participants with diabetes is, instead, a theoretical framework for a distinct occupational therapy approach that could complement existing services. Further research is required to ascertain whether this can work in practice.

The final reflective piece considers a metaphor for the research journey.

***Reflections on a metaphor for the research journey:***

*I more or less finished my quilt in the afternoon - and what is left is patching where the material has frayed and cannot just be sewn up. I put some patches in, but they looked pretty awful so I will replace them with strips of material to make it look a more deliberate patterning of the material. I have enjoyed the quilt more as time has gone on and learned a lot in the process of putting it together. It does seem to make a reasonable metaphor for the research journey - sewed it all up in the prescribed manner as an absolute beginner, made mistakes along the way, didn't like the end product so cut it all up and put it back together in a way that was less perfect but more interesting, I sought advice along the way of the next stages, and was able to have a bit of free rein at the end (with the free sewing) to add more of my own interpretation.*

*The artwork and metaphors have been such a fundamental part of the study. In the exhibiting of the art work, the boat on the felted sea has become quite battered over the last couple of years, quite like how some of the participants feel through life experiences and their condition. It feels like I have gained so many insights which might not have been apparent doing this in a more traditional way. But is there a traditional way after all? Does each researcher, if open enough to the world around, not just bring themselves to this process?*

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# APPENDICES

1. Search strategy for literature review
2. Mixed media art work – responses to exhibition 30/6/14 – 11/7/14
3. Interview schedules
4. Study 2 Participant Information sheet
5. Study 2 Participant consent form
6. Screen shot of Coding in ATLAS ti

## Appendix 1 Search Strategy

<http://www.cumbria.ac.uk/StudentLife/Learning/Resources/Quest.aspx>)

Quest central index includes the following:

University of Cumbria library catalogue; University of Cumbria electronic journals collection; Academic Search Complete; AMED - The Allied and Complementary Medicine Database; British Library Document Supply Centre Inside Serials & Conference Proceedings; Business Source Premier; CAB Abstracts; CINAHL Plus; Computers & Applied Sciences Complete; Education Research Complete; Elsevier Science; Environment Complete; ERIC; GreenFILE; Humanities International Complete; JSTOR Arts & Sciences LexisNexis U.S. Serial Set Digital Collection; Library, Information Science & Technology Abstracts; MEDLINE; NewsBank; PsycARTICLES; PsycBOOKS; Regional Business News; SocINDEX; SPORTDiscus; Teacher Reference Center. Additionally Quest searches other resources including: Directory of Open Access Journals; PubMed; PubMed Central, UK PubMed Central.

(from <http://www.cumbria.ac.uk/StudentLife/Learning/Resources/Quest.aspx>)

Articles were appraised using tools and checklists from the Critical Appraisal Skills Programme (CASP, 2014). The following table gives details of key words (and combinations of these words) that were used in the search:



RESEARCH AREA	KEY WORDS (and combinations of key words)
Occupational therapy	health
	occupation
	occupational focus
	occupational therapy (OT)
	occupation-focused practice
	OT and diabetes
	OT and long term conditions
	OT language
	OT profession
	OT professional behaviour
	OT professional competence
	OT professional development
	OT professional language
	OT professional practice
	OT professional values
	OT professionalisation
	OT theory
	wellbeing
Diabetes	beliefs
	compliance
	diabetes
	diabetes self-care
	diagnosis
	diet
	education; patient education
	embodiment
	empowerment
	gestational diabetes
	intervention
	lifestyle modification, redesign
	lived experience
	mood; depression; anxiety
	patient participation
	physical activity
	prediabetes
	prevention
	problem solving
	psychosocial
	self management
	stigma
	type 1
	type 2

RESEARCH AREA	KEY WORDS (and combination of key words)
Public health	behaviour modification
	care planning
	chronic conditions
	coping
	expert patient
	health behaviour
	health policy
	health promotion
	illness belief models
	illness perceptions, representations
	integrated care
	long term conditions
	patient activation
	patient choice
	primary care
	public health
	self care
	self efficacy
	self management
	wellbeing
Metaphor	creativity
	health
	Identity
	Interpretation
	Language and discourse
	meaning making
	metaphor
	metaphor analysis
	power of metaphor
Research	data analysis
	discourse analysis
	grounded theory
	hermeneutic
	interpretation
	interviews
	IPA
	narrative
	phenomenological
	qualitative
	quality
	quantitative
	rigour

## Appendix 2 Feedback from Exhibition of Mixed Media Artwork (30/6/14-11/7/14)

The artworks featured in this thesis were exhibited at the University of Cumbria Post Graduate Summer School in 2014. The following are anonymised comments from the exhibition:

Date	Comment
30/6/14	A fantastic visual journey of the ups and downs of the PhD and the decisions along the way.
30/6/14	Amazing – inspiring and humbling.
2/7/14	Bel you are so talented and inspirational. I love the diversity in these works. Your work is really accessible and tells the story of PhD work brilliantly.
2/7/14	I am sure all those travelling through their PhD experience will find this totally resonates with their experiences. To represent this “stitched” up is your singular talent.
3/7/14	I saw this at the end of an inspirational conference and was inspired yet again. Thank you for such a marvellous exhibition!
4/7/14	I can relate to the art work and feel it is really helpful in describing the journey. At times I laughed out loud at the recognition! It has made me think about how useful using a more diverse form throughout the process is useful to capture different nuances. I’ll reflect on whether this may help me describe some of the more indescribable processes. Thank you – wonderful!
4/7/14	Thanks Bel, enjoyed not only the images but especially the descriptions of process and reflection.
4/7/14	Simply amazing!
4/7/14	Bel your ability to articulate your learning is so clear! Thank you. I believe it’s a book in itself. Your artwork is visually really pleasing as well as thought provoking. Thank you and many congratulations on your exhibition.
7/7/14	<p>Bel, I really love 3 things about your work and exhibition and will draw inspiration from them all .....</p> <ol style="list-style-type: none"> <li>1. Your journey – sounds like you have had a profound experience and it resonates with my own. It is great that you are so open – it helps others to be able to express their experiences.</li> <li>2. Your techniques – I love the mixed media and textile work. As an early textile artist I have gone ‘wow’ at every one and am keen to get home and get stitching.</li> <li>3. Mixed media data – your exhibition, for me, shows the power of visual data to communicate more than words or to at least enhance words, and I loved seeing such a celebration of this method and validation of my efforts to promote it. Go Bel! Thanks.</li> </ol>

Date	Comment
9/7/14	Bel your work is both thought provoking and inspirational. The process of the research journey is clearly shown that it is both complex and multifaceted. You have my admiration.
9/7/14	Fantastic to see how the emergent creative items have come together in this collective of the journey so far – beautiful.
9/7/14	Amazing Bel.
10/7/14	Bel your work underlines your holistic personality. Art and science combination broadens the way we think and we express ourselves “out of the box” and this is crucial I believe for both fields. The creativity meets the imagination and the passion keeps the positive way of thinking. A sweet feeling remains to the viewer as a result of your work. Please keep up!
10/7/14	Fantastic and inspiring – clearly you are very talented.
11/7/14	Beautifully creative expression of your journey. Much of the expressed emotion I can relate to and enables me to anticipate future aspects of my own journey. The more I view your work the more I discover.
11/7/14	Very interesting approach to documenting / registering / tracing ‘the future present that has not yet passed’ – and your methods for producing the artworks: weaving, quilting, stitching etc I am sure will work as incentives and good working concepts in your approach to metaphor as a tool itself to analyse / research what diabetes is! Very nice!
11/7/14	Beautiful work, very thought provoking and nice to see how others’ journeys are in some ways similar to your own. Thanks.
11/7/14	Really interesting to see your emotional journey. This is a fab way to document this whole process. I do hope you are able to include some of this in your final thesis.
11/7/14	Bel, I’ve been able to sit here by myself when the building is totally quiet. How lovely to experience all your work together as a beautifully presented exhibition. The colours and beauty of your work are striking and perhaps because of the presentation for exhibition it has a calm orderliness. And then when I focus on the detail all the messiness, the hard work and striving and the details spring to life. I think it’s great Bel on many levels.

## **Appendix 3 Interview Schedules**

### **STUDY 1 The Lived Experience of Diabetes**

#### **1. Questions on Demographics:**

Gender, age, type of diabetes, length of time since diagnosis, area of work

#### **2. Can you describe what it is like to live with diabetes?**

(Supplementary questions to probe and for explanation)

### **STUDY 2 Occupational therapists with diabetes**

#### **1. Questions on demographics:**

#### **2. Please start by telling me a bit about yourself**

#### **3. Can you describe your metaphor to me?**

#### **4. How does it convey your experience of diabetes?**

#### **5. In what way was your metaphor helpful (or otherwise) in exploring your experience of diabetes?**

#### **6. How might you apply occupational therapy to your own experience of diabetes?**

#### **7. What do you see as the role of occupational therapy to self-management in diabetes in general?**

#### **8. From your experience of using metaphor in this study, in what way do you think it could be used in occupational therapy practice in relation to diabetes?**

(with supplementary questions to probe and for explanation)

**STUDY 3 Diabetes in the light of the potential occupational therapy role**

1. Questions on demographics
2. Please start by telling me what it's like to live with diabetes
3. Can you describe your metaphor to me?
4. How does it convey your experience of diabetes?
5. In what way was your metaphor helpful (or otherwise) in exploring your experience of diabetes?
6. What would be helpful to support you in managing your diabetes?

(with supplementary questions to probe and for explanation)

## Appendix 4 Example Participant Information Sheet from Study 2

ETH09/04



### Living with diabetes: an occupational therapist's perspective

#### Participant Information Sheet

##### About the study

The overall aim of this research is to understand what it means to you, as an occupational therapist, to live with diabetes, how this impacts on your lifestyle, what problems or successes you have gone through, what support you have had (or would like to have) and generally how you have experienced this condition. The study follows on from a preliminary scoping exercise about living with diabetes in which the data were analysed using a metaphor. This stage of the research explores what metaphors you might use to describe your experience of diabetes and how metaphor might help understanding of this condition. In addition this research aims to explore what you see as the role of occupational therapy in the management of diabetes. The intention is to learn from your experiences to develop further research into how people can be supported by occupational therapy to self-manage diabetes for better health.

##### Some questions you may have about the research project:

###### Why have you asked me to take part?

You have been asked to take part as you have indicated that you are willing to share your experiences as an occupational therapist with diabetes. I would like to explore with you how metaphor helps explain your experience and explore your thoughts on the role of occupational therapy in diabetes self-management.

###### What will I be required to do?

You will be asked to take part in a digitally recorded semi-structured interview, which may last from 30 to 60 minutes, depending how much you would like to share. Prior to the interview I would like you to come up with a metaphor – a picture, a poem, a photograph, an object, or something of your own creation – which encapsulates your experience of diabetes. I will ask you to describe this metaphor in your own words and explain how it conveys your experience. I will follow this up with some clarifying questions to ensure that I understand what you tell me. In the second part of the interview I will ask you about how you might apply occupational therapy to yourself and what you see as the role of occupational therapy for others with diabetes.

**Where will this take place?**

Interviews will take place in your own home or, if you prefer, in an alternative venue at a time that is convenient to you.

**How often will I have to take part and for how long?**

After the initial interview, the transcript of your interview will be shared with you for accuracy and, if you are willing, a further discussion of the themes that emerge from this stage will take place to ensure that they accurately reflect your experience.

**When will I have the opportunity to discuss my participation?**

You can discuss your participation anytime before, during or after the study.

**Who will be responsible for all the information when the study is over?**

I will be responsible, in line with the University of Cumbria's research ethical principles, for ensuring that all information is kept secure and confidential

**Who will have access to it?**

Only members of my research supervision team will have access to the information

**How long will data be kept and where?**

University of Cumbria policy is that the data will be kept for 5 years after the research is completed and published. In line with Ethics Guidelines, data will be kept in a locked cabinet at the university and anonymised electronic data (eg transcripts) will be stored on a password protected university computer.

**What will happen to the information when this study is over?**

After the five-year period hard data will be shredded, in line with the University of Cumbria's approach to research governance. The anonymised digital dataset will be archived (with your consent) in a national research database for the potential use of future researchers.

**How will you use what you find out?**

It is intended that information gained from interviews will be analysed, themes generated and data used to develop further research into how people can best be supported by occupational therapy to self-manage diabetes for better health.

**Will anyone be able to connect me with what is recorded and reported?**

No, your details will remain confidential so that they cannot be attributed to you.



**How long is the whole study likely to last?**

This stage of the study is likely to last for a few months.

**How can I find out about the results of the study?**

An initial summary of the research findings will be sent to you. This also gives you the option to comment on the themes that emerge, if you wish to remain involved. It is then intended to publish the results of this scoping exercise in an academic journal and a copy will be made available to you.

**What if I do not wish to take part?**

Your participation in the study is entirely voluntary.

**What if I change my mind during the study?**

You are free to withdraw from the study at any time without having to provide a reason for doing so. In addition you will have certain editing rights during the recorded interview, for example if you wish to retract something you have just said, it will be wiped from the recording. You can also request that your data (from the interview transcript) be withdrawn up until the point at which the results have been published.

**Will I need to sign any documentation?**

You will be asked to sign a consent form before participating in the study.

**Whom should I contact if I have any further questions?**

Please contact the researcher directly (details below).

**Complaints**

All complaints from the participants are in the first instance to be directed to the Director of Research Office and Graduate Studies, University of Cumbria, Bowerham Road, Lancaster, LA1 3JD

***Researcher Contact Information:***

*Bel Youngson  
Faculty of Health & Science  
University of Cumbria  
Bowerham Road  
Lancaster, LA1 3JD*

*Tel:  
Mobile:  
Email:*

## Appendix 5 Example Consent Form from Study 2

ETH09/04a



### Living with diabetes: an occupational therapist's perspective

#### Participant Consent Form

**Please answer the following questions by circling your responses:**

Have you read and understood the information sheet about this study? YES NO

Have you been able to ask questions about this study? YES NO

Have you received enough information about this study? YES NO

Do you understand that you are free to withdraw from this study at any time, and without having to give a reason for withdrawal? YES NO

Your responses will be anonymised before they are analysed.

Do you give permission for members of the research team to have access to your anonymised responses? YES NO

Do you agree to take part in this study? YES NO

Do you agree to the interview being digitally recorded? YES NO

Do you agree to your metaphor being photographed? YES NO

Do you agree to the archiving of your anonymised responses for possible future research? YES NO

Your signature will certify that you have voluntarily decided to take part in this research study having read and understood the information in the sheet for participants. It will also certify that you have had adequate opportunity to discuss the study with an investigator and that all questions have been answered to your satisfaction.

**Signature of participant:**..... **Date:**.....

**Name (block letters):**.....

**Signature of investigator:**..... **Date:**.....

Please keep your copy of the consent form and the information sheet together.

#### **Researcher Contact Information:**

*Bel Youngson  
Faculty of Health & Science  
University of Cumbria  
Bowerham Road  
Lancaster, LA1 3JD*

## Appendix 6 Screen Shot of ATLAS ti coding

The screenshot displays the ATLAS.ti software interface. The main window shows a text document titled "P16: STA" with interview transcripts. The text includes the following segments:

018 N: Yeah, so then my blood sugars after I had delivered, I was fine. When they tested me right after and then I kind of intermittently used my meter and just test, and I wasn't having any difficulties. Since I've had a few, like the last two or three years, just slightly over on a fasting, when I get my regular blood work done, they like it to be less than 100 and maybe it was 102, something like that. So I know that I'm at risk just because of having had gestational diabetes.

019 B: And how does that feel being at risk

020 N: It's interesting because when we talked, I thought about it intermittently, I was so disciplined with the pregnancy because I was very motivated by having a healthy child and I find it interesting, because I pay attention to it, I know that I'm at risk and I feel like I make positive lifestyle choices, well I try to. It's often a challenge. But I noticed I always kind of go 'huh!'. It's harder for me to like say 'No I don't think I'll have that ice cream' when it's just on me. (laughs). But I've thought about that and realised you know it's because I still have her, I still want to be a parent to her, I know the negative consequences of diabetes, but thinking about getting ready for this, getting my picture together, I thought, thinking like an OT, how much stronger my volition felt for management then than it does now, even though I know I'm at a higher risk than other people my age who don't have the same history. So there's a little cognitive dissonance there between (laughs) would I do it for just me versus when I was pregnant and needing to do it for my child.

021 B: I mean it was a completely different situation then, wasn't it, really

022 N: Yes, it was, it was very much a different situation and it really, when I think about the difference in lifestyle because, like I said, I totally let go of two other major roles that I had in my life at that time, my work role as a professor and my role as a student in the PhD department. So it was just very clear, that's not part of my life right now. Even without those things I know I spent, I mean all my time was focussed on self management. What time am I getting up, checking my sugars, I can't go to this because I've got to wait here to get my sugar, I've got to get my food in the right way and I also took to having a nap and I was also doing things like prenatal yoga, exercise and so those things, interspersed with washing baby clothes, doing things, getting ready, all that kind of pre pregnancy things, doing to get ready for the baby, that really consumed all of my time.

U23 B: And it was simply about having that baby, making sure that everything was alright.

U24 N: Yeah. So when I then think about that, I think 'how was that balance achieved? Literally not having the role demands of those other two roles made it feasible and not overly stressful, I guess. I mean it had its own stress just because of worry and concern and those kind of emotional pieces but I wasn't needing to balance that with other demands. So I felt I could really be very, follow the regimen that I needed, and it felt balanced. Even though it felt much more structured than often I am, particularly as I love eating, I

The right-hand pane shows a coding tree with the following categories and sub-categories:

- Interviewer questions
  - Nancy
  - Finlay - embodiment-
- Interviewer questions
  - Nancy
  - Discourse: Control-
  - Finlay - relationships-
  - MOHO occupational identity-
  - Occupational therapy - own management-
  - MOHO volition
  - Finlay - project-
- Interviewer questions
  - Nancy
  - MOHO occupational adaptation
  - MOHO occupational identity-
  - MOHO occupation of diabetes self management
  - MOHO occupational identity-
  - Finlay - relationships-
  - metaphor - conventional
- Interviewer questions
  - Nancy
  - Discourse: Balance-
  - metaphor-
  - Discourse: Balance-
  - MOHO occupational adaptation
  - MOHO occupational identity-

The bottom status bar indicates: "P16: STAGE 2 PARTICIPANT 8 checked by Nancy.docx" and "Size: 100% Rich Text < Default".